

Nurses transforming the spousal caregiving experience : health as expanding consciousness and patients recovery at home following cardiac surgery

Author: Carrie Edgerly Macleod

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Boston College

William F. Connell School of Nursing

NURSES TRANSFORMING THE SPOUSAL CAREGIVING EXPERIENCE:
HEALTH AS EXPANDING CONSCIOUSNESS AND PATIENT RECOVERY AT
HOME FOLLOWING CARDIAC SURGERY

a dissertation

by

CARRIE EDGERLY MACLEOD

Submitted in partial fulfillment of the requirements

for the degree of

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ABSTRACT

Nurses Transforming the Spousal Caregiving Experience: Health as Expanding Consciousness and Patients Recovery at Home Following Cardiac Surgery

Dissertation by: Carrie Edgerly Macleod PhD (c), RN

Dissertation Chair: Dorothy A. Jones EdD, RN, FAAN

The purpose of this qualitative research study was to answer the following questions: What is the life pattern manifested by individuals caring for spouses who have had coronary artery bypass surgery? What are the thematic expressions of life patterns among individuals caring for spouses who have had coronary artery bypass surgery?

The theoretical framework guiding this study was Margaret Newman's Health as Expanding Consciousness. The research method created by Newman facilitated the understanding of the individual participant's experience, pattern identification, similarities in pattern across participants and the potential for expansion of consciousness. The study sample included ten women and two men whose spouses were recovering at home following cardiac surgery. These twelve spousal caregivers shared their life stories and their spousal caregiving experience in the first two weeks at home following their spouses discharge from the hospital.

There were various levels of potential for expansion of consciousness for these spousal caregivers. Looking across participants six themes emerged from the data. First, disruption in the spousal caregivers' roles and responsibilities impacts the relationship between the spousal caregivers and their spouses and shifts life patterns. Second, spousal caregivers face coping challenges with changes in lifestyle and response to illness. Third, Spousal caregivers experience vigilance in an effort to ease the uncertainty of the

recovery process. Fourth, knowledge helps spousal caregivers gain a sense control in the face of uncertainty. Fifth, mutuality within the partnership of nurse and the spousal caregiver relationship impacts the potential for transformation. Sixth, Spousal caregivers' awareness of their life pattern gives meaning and offers the caregivers a new perception on life they have left to live.

Findings from this study have important implications for nursing theory, practice, research, education and health care policy. The study adds empirical support to Newman's Theory of Health as Expanding Consciousness and provides a new way to examine spousal caregiving and the nurse-client relationship.

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I dedicate this work to my family. To my husband David for the many sacrifices that you made during this experience. You are an incredible source of strength and love and I could not have done this without you. To my daughters, Anne and Katherine, you are my reason for living; thank you for your patience and smiles these past four years. I thank my mother for my love of education and my father who helped me understand the challenges of caring for someone you love. And lastly, to my grandfather, Grover C. Waterhouse, who taught me that caring truly is about presence, listening, mutual respect and love. Grampa, you continue to inspire me from the beyond and I thank you for all your encouragement, love and for how proud you were of me.

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CHAPTER ONE

INTRODUCTION

For the foreseeable future, coronary artery disease (CAD) will continue to be the largest element of global disease burden (WHO, 2004). Over thirteen million individuals are diagnosed with this disease each year, accounting for 6.4% of the American population. In 2003, CAD was listed as the number one discharge diagnosis (2,090,000 cases), with 53% of these discharged individuals 65 years and older. In the years between 1997 and 2003, CAD was listed as the top “short-stay hospitalization diagnosis” and was demonstrated to have a 27% increase within that time frame. Currently, one in every five deaths occurring in the USA is due to CAD, accounting for over 600,000 deaths of American men and women each year (Center of Disease Control, 2006). At this point in time, CAD is the number one killer of Americans, with the management of cardiac disease costing over \$300 billion dollars a year (American Heart Association, 2005).

Background of the Study

Within the coronary artery disease (CAD) patient population, there are two significant trends. The first is the increasing age of the patient undergoing coronary artery bypass graft surgery. In 1999, the average age was 65; currently, it is 75 years of age. Because of the general population trends related to aging, it is projected that there will be exponential increases in the number of people requiring treatment for this health problem in the future (Miller & Grindel, 2001). The second trend involves the shortened length of hospital stay following CABG surgery. Changes in health care reimbursement and new technology have significantly decreased hospital length of stay, resulting in many patients

completing their recovery either in a rehabilitation facility or at home (Miller & Grindel, 2001). Today, the typical length of postoperative stay in the hospital for patients after CABG has dropped from one to two weeks in the early 1990's to the present three to five days (Yin, Zhou, & Bashford, 2002).

Family caregivers play a significant role in the recovery process of these postoperative patients. Within the United States, family caregiving is conservatively estimated at costing \$257 million a year, more than twice the amount of paid home care and nursing home services combined. Over 22.4 million homes currently provide care to persons over the age of 50. This number is expected to increase to 37 million by 2050 accounting for an 85% increase since 2000. Thirty percent of caregivers caring for an elderly family member are themselves aged 65 or over (U.S. Department of Health and Human Services, 2003). It is estimated that the caregiving that these families provide is valued at approximately \$306 billion a year, nearly twice as much as the amount spent on homecare and nursing homes combined (Arno, 2006). Overall, the caregiving experience is not without ramifications for the family caregiver.

While the hospitalization may only last three to five days, it is necessary for healthcare providers to prepare the patient and the family caregiver for the transition to home. Discharge to home earlier tends to be viewed more positively by the patient. The spouse, on the other hand, often expresses fear around their inability to handle both the physical and emotional needs of his or her spouse (Engelmann, Rousou, Flack, Deaton, Humphrey & Ellison, 1994), increased psychological distress and the need for support (Moore, 1997).

A recent study in the New England Journal of Medicine indicated that caring for a sick spouse can raise a caregiver's risk of death by 20% (Christakis & Allison, 2006). In addition, challenges around assuming increased responsibility for medications, pain control, and symptom management of an individual who has just experienced major surgery (Jaarsma, Kastermans, Dassen & Philipsen, 1995) create new sources of stress for the caregivers after hospitalization. Within the current health care delivery system, spousal caregivers are now performing care in the home setting that has historically been relegated to the hospital setting less than a decade ago (Knoll & Johnson, 2000; Stolarik, Lindsay, Sherrard, & Woodend, 2000; Yin et al., 2002). This increased responsibility is often not addressed at the time of hospital discharge and can threaten the caregiving experience for both the patient and provider at home.

To date, the research on spousal caregivers has focused on the caregiver's perception of the spouse's recovery and issues around discharge planning, knowledge deficits and task performance. There is limited understanding of this caregiving experience in relation to these caregivers' own life pattern and personal meaning. Gaining insight into this experience through the perspective of Newman's Health as Expanding Consciousness will increase nursing's understanding of caregivers and promote intervention strategies that will impact the caregiving experience.

Purpose of the Study

The aim of this study is to gain an understanding of the lived experience for the spousal caregiver of the postoperative surgery patient following CABG surgery. Understanding the perspective of the caregiver over his or her lifetime may inform the

caregiving experience and enable nursing to identify the issues and meanings to assist these spousal caregivers during a potentially stressful, overwhelming period.

Research Questions

For the purpose of this study, two questions were posed: What is the life pattern manifested by individuals caring for spouses who have had coronary artery bypass surgery? What are the thematic expressions of life patterns among individuals caring for spouses who have had coronary artery bypass surgery?

Theoretical Framework

The Unitary-Transformative Paradigm

The unitary-transformative paradigm views a phenomenon as a unitary, self-organizing field embedded in a larger self-organizing field. A phenomenon is identified by pattern and by its interaction with the larger whole (Newman, Sime & Corcoran-Perry, 1991). Pattern is the identifying characteristic of a person's wholeness. Manifestation of this wholeness is reflected in the interaction of person and environment which in turn demonstrates the uniqueness of a person (Picard & Jones, 2005).

According to Fawcett (1993), the unitary-transformative paradigm is characterized by the following. Human beings are unitary and evolving as self-organizing fields; human fields are identified by pattern and by interaction with the larger whole; change is unidirectional and unpredictable; systems move through stages of organization and disorganization to more complex organization; and emphasis is on personal knowledge and pattern recognition.

In the context of nursing, this paradigm embraces wholeness and pattern and reveals a world that is moving, evolving and transforming. The whole is greater than the sum of its parts and exhibits unique qualities that cannot be fully understood by looking at parts. Nurses approaching an individual from the Unitary Transformative perspective recognize the whole while attending to the part. Nurses enter into the whole through the part. The recognition of meaning and pattern reveals the evolving nature of the whole and honors the undivided wholeness of the human health experience (Newman, 2007). .

Health as Expanding Consciousness

Margaret Newman's theoretical framework, Health as Expanding Consciousness (HEC) (Newman, 2007) guided this study. Within this theory, human nature is viewed as "unitary, an open energy system that is in a continuous interconnectedness with the open system of the universe and is continuously engaged in an evolving pattern of the whole" (Newman, 1999, p.41). The major assumptions of the theory are:

1. Health is the unitary process of the whole
2. Disease and nondisease are expressions of the whole
3. Pattern is the evolving human/environment process characterized by meaning
4. Consciousness is the informational capacity of the whole revealed in the evolving pattern of the whole.

Health as Expanding Consciousness embodies the following concepts: health, pattern, consciousness, movement, time and space. Health is a fusion of opposites, disease and nondisease, that is "patterned, emergent, unpredictable, unitary, intuitive and

innovative” (Newman, 1999, p. 13). Health includes disease as a meaningful manifestation of the pattern of the whole based on the premise that life is an ongoing process of expanding consciousness. It is the process of becoming aware of the interconnectedness of self and environment. Within this awareness, there is an opening up to possibilities of alternative actions and ways to respond to the world. For Newman, the essence of health is the recognition of pattern (Newman, 1999).

Pattern is what individualizes a person and is essential in the act of energy exchange and transformation. Newman (1991, p. 163) stated “Whatever manifests itself in a person’s life is the explication of the underlying implicate pattern...the phenomenon we call health is the manifestation of that evolving pattern”. Pattern reflects the dynamic interaction between a person and the environment, the constitute of health.

Consciousness is viewed as the informational capacity of the system, the ability of the system to interact with its environment. It is cognitive, affective and is the interconnectedness of the entire living system. Time, movement and space are all correlates of consciousness. An individual’s life is seen as a progression toward higher levels of consciousness; expansion of consciousness is the essence of life and health. A person may be identified as a pattern of consciousness which includes awareness of self within a larger system of consciousness (Newman, Smith, Pharris, Jones, 2008).

Movement is reflected in the individual’s perception of reality and is the channel that the individual uses to become aware of self. Humans are in constant state of motion and are constantly changing. This movement through time and space gives the individual

a unique perception of reality and the ability to experience the world. It is considered a means of communication (Newman, 1997).

Time is defined as perceived duration; it is holographic and intimately linked with space. Newman elaborates that this relationship with space is complementary but inversely proportional: as one's life space is decreased, one's perception of the duration of time is increased. Newman (1999, p. 62) states "each moment has an explicate order and also enfolds all others, meaning that each moment of our lives contains all others of all time".

A key factor in the evolution of HEC was Newman's conceptualization of time. Initially viewed from a subjective/objective vantage, time became viewed as holographic. Newman has described this evolution of her theory as a movement from "linear explication and testing of the concepts of time, space, and movement to an elaboration of interacting patterns as manifestations of expanding consciousness" (1997, p. 36). In the theoretical framework of HEC, space, time and movement were linked, as evidenced by the proposition "the intersection of movement-space-time represents the person as a center of consciousness and varies from person to person, place to place, and time to time" (Newman, 1999, p.49). Pattern and movement were correlated in the statement, "The rhythm and pattern, which are reflected in movement, are an indication of the internal organization of the person and his perception of the world. Movement provides a means of communication beyond that which language can convey" (Newman, 1979, p. 63).

We come into being from a state of consciousness, are bound in time, find our identity in space, and through movement learn the 'law' of the way things work

and make choices that ultimately take us beyond space and time to a state of absolute consciousness (Newman, 1999, p. 46).

Theoretical Assumptions of Health as Expanding Consciousness and the Current Study

1. Surgery and the subsequent postoperative recovery have a disrupting effect on the lives of both the care recipient and the spousal caregiver.
2. This disruption provides an opportunity for a choice point to be recognized in these individuals' lives. Life changes and opportunities for self awareness and transformation can occur while caring for the patient recovering from surgery that may lead to the expansion of consciousness.
3. Spouses as caregivers of postoperative CABG patients are most knowledgeable about this experience and share this knowledge and meaning willingly and honestly.
4. The nurse as researcher enters the relationship with the client with intentionality in an effort to understand the meaning of this experience. By understanding this meaning, the nurse researcher is able to construe a pattern that is reflective of the client's life.
5. Within research as praxis, the nurse becomes integral to emerging pattern. The intentional presence of the nurse enhances discovery and uncovering of meaning to the participants.
6. Pattern awareness creates opportunity for choice action and transformation.

Significance of the Research

The concept of informal caregiving is one that has increasing importance and effect on the healthcare system and the lives of those individuals who assume the

caregiving role. Within the cardiac surgery population, there is an increased dependency on the spouses of postoperative patients to assume the care earlier in the recovery course. With earlier discharge to home and the increasing age of the patient and spouse, this responsibility is made even more overwhelming. It was the goal of this qualitative study to obtain a deeper understanding of the spousal caregiver's experience. This knowledge provides a new conceptualization of spouses who assume the caregiver role and of caregiver burden. A deeper insight into the caregiver's perspective can direct innovative models of intervention and assessment as well as instrument development for both the caregiver and recipient. There was also the potential to directly affect the rehabilitation and recovery of the postoperative care recipient and enhance their perception of the spousal caregiver. With this knowledge in place, increased transformational possibilities for the spousal caregiver and the nurse were realized.

It was also the purpose of this study to contribute to further nursing research, practice and theory. The unique perspective of the spousal caregiver provided deeper, richer information that contributed to the expansion of Newman's theory of expansion of consciousness. By using Newman's research methodology, research as praxis, a hermeneutic dialectic methodology, the study expanded upon the meaning of the lived experience of the individuals living and caring for patients recovering from surgery. This study added to the growing body of research that supports the theory of Health as Expanding Consciousness.

In addition, this study added to existing research and knowledge regarding caregiving and created new knowledge about the caregiving experience. This knowledge

generated knowledge that has the potential to decrease caregiver stress. The information obtained from the interactions with these individuals has the potential to influence the practice of nursing, healthcare delivery and future healthcare policy.

Chapter Summary

This study will explore the meaning of the lived experience of the spousal caregiver of the postoperative coronary artery bypass patient. This chapter presented the background of the study, the purpose of the study, the research questions, the theoretical framework, assumptions and the significance of the research.

CHAPTER TWO

REVIEW OF THE LITERATURE

The literature relevant to the study of spousal caregivers is reviewed in this chapter. An overview of family caregiving focusing on the caregiving process is provided, specifically within the cardiac surgery population. The review also includes literature relevant to cardiac surgery including the changing patient demographics, hospitalization stay and the increased shift of care to the home setting. Research regarding the recovery process from cardiac surgery in both the hospital and home setting, as well as the effects of this surgical intervention in the setting of co-existing chronic illnesses is presented. Existing intervention studies focusing on the coronary artery bypass population were reviewed. Margaret Newman's Health Theory as Expanding Consciousness has been further elaborated on along with a review of research studies that support the use of Health as Expanding Consciousness as a framework to guide research.

Cardiac Surgery

Coronary artery bypass grafting (CABG) is the preferred surgical management procedure used for the majority of individuals with coronary artery disease (CAD). The procedure involves bypassing occluded coronary arteries with the internal mammary artery, radial artery or the saphenous vein. The intervention relieves angina by increasing myocardial blood flow to the coronary tissue. In 2005 nearly 500,000 CABGs were performed on 261,000 individuals in the United States (American Heart Association, 2005). Within the last decade, availability of medical and surgical interventions for

individuals affected by CAD has increased. This is due primarily to advances in surgical technology, such as off-pump bypass procedures, rapid ventilator weaning and new pharmaceuticals resulting in improvements in patient outcomes (Society of Thoracic Surgeons, 2004). The recent revival of off pump coronary artery bypass surgery (OPCAB) has been observed and is associated with an aging of the CAD population, increased surgical risk, and technical improvement. There are contraindications to this procedure including unstable hemodynamics, intramyocardial left anterior descending artery, and reoperation with extensive adhesions (Cartier, 2003).

Changes in health care reimbursement and advances in technology have impacted surgical procedures, reduced complications and significantly decreased hospital length of stay, resulting in many patients completing their recovery either in a rehabilitation facility or at home (Miller & Grindel, 2001). Typically, the length of postoperative stay in the hospital has dropped from one to two weeks in the early 1990's to three to five days currently (Yin et al., 2002).

CABG Demographics

According to the US Census Bureau, the United States population is aging rapidly. There are dramatic shifts in the population structure and new projections that the population aged 65 and over is expected to double in size within the next 25 years. By 2030, one out of every five Americans, approximately 72 million people, will be 65 years or older. The age group 85 and older is now the fastest growing segment of the U.S. population (US Census, 2006). And although the general health of these aging individuals is improving, there has been an increase in chronic illness noted. Heart disease and cancer

are the leading causes of death within this population, with death rates varying by age, sex, and race. These variables had a significant impact on the number of elderly individuals who may require surgical intervention. In addition, statistics indicate that the current rise in the percentage of people considered obese has grown in men from about 24 to 33 % and in women from about 27 % to 39 % (National Vital Statistics, 2005). This factor has the potential to increase the need for coronary artery bypass graft surgery in the coming years.

Currently, the incidence rate for a three-vessel coronary artery bypass graft in an individual 65 years of age or older (1.95 procedures per 1,000 persons per year) is more than twice as high as in a 45 to 64-year-olds (0.82 procedures per 1,000 persons per year) (American Heart Association, 2005). Although there is an associated prolonged hospital stay for elderly patients, cardiac surgery can be and is performed in patients 85 years and older with good results. Consistent successful outcomes can be expected in this patient population with selective criteria identifying risk factors (Davis et al., 2004).

Cardiothoracic surgeons care for predominantly older patients. In cardiothoracic surgery, 70% of procedure-based work is derived from patients 65 years old or older. Over the next two decades, the growth in surgical work in this field is forecasted to be around 42% (Etzioni, Liu, Maggard, & Ko, 2003). Noninvasive therapies such as PTCA and stenting thus far have failed to decrease the need for cardiac surgery. When the costs and benefits of medical technological advances in the treatment of coronary artery disease are examined, the rapid growth of coronary angioplasty and stent technology

have had no discernible impact on the growth of coronary artery bypass surgery (Cutler & McClellan, 2001).

Predictors for Success Outcomes: The Effect of Comorbidities

The success of CABG procedure is highly dependent on the quality of health of the patient population. Late referral for surgery due to gender bias, a higher number of comorbidities and smaller coronary arteries all contribute to poorer outcomes (Hogue, Sundt, Barzilai, Schecthman, & Davil-Roman, 2001). Coronary artery disease in women is associated with higher morbidity and mortality than in men due to specific differences in pathophysiology, traditional and psychosocial risk factors, symptom presentation, treatments, and outcomes (Eastwood & Doering, 2005). Over 150,000 women annually undergo CABG surgery. There is considerable evidence to suggest that the female population generally has a greater operative risk than the male population. Data from The Society of Thoracic Surgeons National Cardiac Surgery 2002 Database reveal a CABG operative mortality of 3.54% for women versus 2.15 % mortality for men. (Society of Thoracic Surgeons, 2003).

The best predictive preoperative factors for increased morbidity associated with CABG are emergency operation, diabetes, cardiac rhythms other than sinus rhythm on the electrocardiogram or recent myocardial infarction, hypertension, low ejection fraction (< 0.49), age greater than 70 years, decreased renal function, chronic pulmonary disease, cerebrovascular disease, tobacco use and obesity (Kurki & Kataja, 1996). Other pre-existing comorbidities with significant impact or risk include the use of preoperative intra-aortic balloon pump, peripheral vascular disease (Ott et al., 1997), previous or failed

percutaneous transluminal angioplasty (Lazar et al., 1997) and previous cardiac surgeries (Dunstan & Riddle, 1997; Ott et al., 1997). CAD risk factors include but are not limited male sex, high blood cholesterol, [diabetes mellitus](#), [high blood pressure hypertension](#), and cigarette smoking (Society of Thoracic Surgeons, 2005) and are themselves significant comorbidities.

Postoperative Complications

Research reveals age, gender and preoperative cardiac status significantly affect individual recovery of the CABG patient (Gortner et al., 1988). Postoperative complications from CABG procedure may be multiple and tend to be higher in the older CABG population; this is because older patients usually have more risk factors prior to the procedure. The most commonly occurring postoperative complications include cardiac conduction defects such as atrial fibrillation, atrioventricular block, and ventricular tachycardia (Cook et al., 2005), cardiac surgery reoperation due to hemorrhage or cardiac tamponade (Dunstan & Riddle, 1997; Ott et al., 1997), neurological complications including psychosis, delirium and cerebral vascular accident (Bendszus et al., 2002); pneumonia; sternal and/or leg wound infections, further postoperative operative procedures including but not limited to reoperation and general surgical intervention (Society of Thoracic Surgeons, 2004).

Graft patency presents a critical issue for this surgical population. Early and late graft failure remains a recurrent problem (Metcalf, Lip, & Dargie, 1994). Symptomatic occlusion of a graft may occur in as many of 15% of patients within the first year and after a decade, only 50% of grafts may be functionally patent (Fitzgerald, Prochaska, &

Pransky, 2000). A significant reduction of early graft occlusion has been made possible by using platelet inhibitory drugs and/or anticoagulant therapy. The use of the internal mammary artery grafts (IMA) demonstrates an excellent long-term patency preventing late graft failure. Additionally IMA grafts demonstrate improved life expectancy and reduced the risk of myocardial infarction (Mills, Gahtan, Fujitani, Taylor, & Bandyk, 1994). Still, a minority of these patients require repeat surgery, usually ten or more years after their original operation. It is predicted that this number of repeat surgeries will continue to decline as it has been in the past years due to a number of improvements in surgical procedures (Society of Thoracic Surgeons, 2006).

Despite an increasingly aging patient population, extraordinary modifications of clinical pathways are not considered necessary for success with elderly patients. Currently, it is not known whether there are differences in outcomes between comparatively older and younger patients when they are matched by risk classification (Miller & Grindel, 2001). Regardless, the increased length in hospital stay associated with postoperative complications appears to be attributed largely to the increased incidence of atrial fibrillation (Paone, Higgins, Havstad, & Silverman, 1998).

Recovery for the Postoperative CABG Patient and Caregiver

The transition from hospital to home is identified as a period of intense stress and burden for CABG patients and their informal caregivers (Miller & Grindel, 2001; Theobald & McMurray, 2004). There is ongoing research linked to nursing interventions during this critical phase of recovery focusing on helping individuals with potential psychological stressors. In a study focusing on recovering CABG patients, individuals

were contacted by phone at week one and week six after discharge. They were asked

"What do you want your nurses and doctors to know to help them do a better job?"

Findings included the following: Patients wanted a smoother transition to home, to be recognized as an individual, and be prepared honestly for their experience with specific information (Doering, McGuire, & Rourke, 2002).

Unfortunately, the recovery trajectory for patients following CABG is often not smooth; neither is the attempt to adequately educate the patient and family for discharge to home (Theobald & McMurray, 2004). Knowledge about managing patient care after surgery has been the central focus of nursing care for the patient and their family caregivers. Nursing research included studies that have addressed knowledge related to wound care, pain management, activity, diet, medications, return to work and sexual activity (Whitman, 2004). Other significant research focusing on patient role and family adaptation to life after surgery as well as development of coping strategies for the family unit to address patients' and caregiver responses are lacking in literature (Whitman, 2004).

First Weeks after Discharge to Home

The first week post-hospitalization is considered to be the most stressful for both patients post coronary artery bypass graft and their family caregivers facing physical and emotional challenges in caring for the patient at home. Research during this timeframe has focused on complications, symptom management, and resumption of personal care and physical function (Goodman, 1997). Physical concerns including life-threatening complications, activity and energy levels, wound healing, pain/discomfort, shortness of

breath, fluid retention, medication management, and gastrointestinal disturbances have been studied by researchers (Brennan et al., 2001; Goodman, 1997; Hartford, 2005). Wu (1995) found the 75% of the symptoms associated with recovery from CABG surgery occur within the first two weeks of discharge. In addition, only 10% of patients report continued complaints after the one month recovery point.

The initial days at home following surgery have the potential to produce anxiety, anger, depression, mood swings and sleep disturbances as the recovering patient and caregiver attempt to successfully adapt to the patient recovering at home (Brennan et al., 2001). Davies (2000) reports that 40 to 70% of spousal caregivers of patients following bypass surgery expressed a need for information regarding “what is typical and what is not” in the weeks following surgery, how to manage the pain and the fatigue of a postoperative patient, and the unexpected overwhelming responsibility that is incurred with caregiving process have not been addressed.

During this postoperative period at home, research has reported on patients’ and families’ anxiety about speed of discharge and the first day at home. While physical concerns predominated during the first week at home, concerns later shifted to long term, future-oriented issues. By the second month following discharge, most patients were planning for return to normal activities, and several began to contemplate lifestyle changes (Hartford, 2005).

A recurrent issue reported in the literature links gender and complications in the early recovery phase after surgery. There are multiple studies focusing on the influences of gender on the physical recovery process (Angus, 1996; Babayan et al., 2003; Eastwood

& Doering, 2005; Hogue et al., 2001; Ingersoll-Dayton & Raschick, 2004; King, 2000; Steuer et al., 2002). From a caregiving perspective, female patients appear to rely on their spouses for help less frequently than do male patients. Male caregivers are more frequently employed outside the home and in lower status jobs. However, data suggests that postoperatively females are more functionally limited, and report lower life satisfaction and social support, than men (King, 2000).

Studies have reported that at four weeks post discharge, recovering CABG patients begin to focus on regaining independence in their activities of daily living and building some activity tolerance (Barnason, Zimmerman, Anderson, Mohr-Burt, & Nieveen, 2000; Gortner et al., 1989; Rumsfeld et al., 2001). Patient concerns during the first postoperative month continue to center around pain relief, sleep promotion, psychological support, practical physical help and community support (Goodman, 1997). Concurrently, this is also the timeframe when readmission to the hospital may occur.

Readmission after Discharge to Home

The risk of readmission is highest early after surgery and then gradually decreases the longer the recovery is “stable”. Risk groups for readmission include the elderly, females, active smokers, persons with diabetes, previous myocardial infarction, unstable angina, dyspnea, and severe left ventricular dysfunction. New York Heart Association functional class IV, bypass time of two hours or more, and length of stay each independently also increased the risk of readmission (Steuer et al., 2002). The most frequent reasons for readmission include atrial fibrillation (Mitchell et al., 2005) chest pain with or without shortness of breath (Bradshaw, Jamrozik, Le, Gilfillan, &

Thompson, 2002), heart failure (Babayan et al., 2003; Steuer, Granath, de Faire, Ekbom, & Stahle, 2005) incisional infection (Celkan, Ustunsoy, Daglar, Kazaz, & Kocoglu, 2005; Sharma, Berriel-Cass, & Baran, 2004), pleural effusions (Payne et al., 2002) and analgesic reactions (Sabourin & Funk, 1999). Readmission to the hospital is also more likely for those patients who have complications during their initial hospital stay and those who require at least partial assistance with bathing, dressing, feeding, or toileting upon discharge to home (Redeker & Brassard, 1996).

First to Second Month after Discharge to Home

During the two month period after surgery, recovery focuses on return to work activities (Angus, 1996; Barnason et al., 2000; Hartford, 2005) and resumption of social and sexual activities (Brennan et al., 2001; Gilliss & Rankin, 1988). At six months postoperatively, the emphasis of patient recovery is on return to work activities and long-term lifestyle changes (Brennan et al., 2001; Theobald & McMurray, 2004). In one study focusing on the first six months following CABG, 82 cardiac patients were interviewed six months after discharge to home. Questions focused on problems experienced in early recovery and what information was needed during this period. All but one of the 82 patients stated they had experienced problems during the first six months after discharge. Most problems were described as: emotional reactions (59%), changes in physical condition (59%), deleterious effects of treatment (56%) and convalescence (54%). Topics on which most patients needed additional or different information were: deleterious effects of the treatment (26%), physical condition (24%), risk factors (24%),

convalescence (24%) and knowledge of the disease (24%) (Jaarsma, Kastermans, Dassen, & Philipsen, 1995).

Many patients following CABG surgery are sent home with the assistance of visiting nurses. Studies indicate that dysfunctional health patterns primarily in the area of activity/exercise are common. Visiting nurses usually monitor cardiopulmonary status, provide wound care, and give instructions on diet, medications, and cardiac regimen. The duration of these home care visits was shorter for patients who were married and for those who reported weakness, tiredness, or fatigue as a chief complaint. A major issue for the CABG patient and caregiver at home is that informal caregivers report a lack of continuity care after discharge from the hospital. These caregivers report a distinct disparity in the knowledge base and a lack of resources available to them once they are in the community dealing with medical generalists and the visiting nurses during the months following surgery (Davies, 2000).

Third to Six Month after Surgery

Gender is an important issue in the later recovery trajectory period. At three months postoperatively, there may be fewer significant differences in cardiac surgery recovery outcomes, but women continue to report lesser social support. There is also a significant difference in the nature of work to which women return following their surgery (Aberg, Sidenvall, Hepworth, O'Reilly, & Lithell, 2004). In general, CABG surgery is often associated with lower functional gains and higher readmission rates in women as compared with men six months after operation (Vaccarino et al., 2003).

There is little research regarding the effect of the recovery trajectory on the family caregiver. Intervention research has the potential to demonstrate the need to individualize interventions based on the context of care (Naylor, 2003). This is critical if researchers are to understand which aspects of an intervention are responsible for therapeutic changes (Burgio et al., 2001).

Greater than One Year after Surgery

In the later postoperative phase, over one year after surgery, a predominance of patients report a significant level of improvement in physical function and energy level. Nearly 70-80% desire to and often return to work within the year. Those individuals who return to work often demonstrate greater positive and less negative affect, somatic complaints and cognitive complaints (Boudrez & De Backer, 2000).

Five years after CABG surgery, anginal symptoms may return in up to 15% of patients, and 10% may have ischemic events. Up to 27% continue to report forgetfulness but have no measurable impairment of neuropsychological testing (Charlson & Isom, 2003). There appears to be increased cognitive deterioration after CABG surgery than in other surgical procedures due to a variety of causes including cardiopulmonary bypass time, surgical-related trauma, genetic susceptibility, microembolization, other vascular or ischemic changes, and temperature during surgery (Raja, Blumenthal, & Doraiswamy, 2004). Although it appears that overall emotional functioning or mental health generally improves six to twelve months after surgery (Charlson & Isom, 2003), cognitive impairment may present significant implications in the immediate with preparation for the transition to home due to the impaired ability of the postoperative patient to retain

information at discharge (Barnason et al., 2000) and later on as the individual attempts to re-integrate into his or her previous lifestyle.

Chronic Illness, Coronary Artery Disease and the Postoperative CABG

Chronic illness is defined as having one or more of the following characteristics. Namely, it is long-term or permanent; leaves a residual disability; causes, natural course, and treatments are ambiguous; a degenerative process; requires special training and rehabilitation; and requires a long periods of supervision. Control over acute, infectious illnesses has led to longer life spans for many populations, but has also resulted in growing rates of chronic illness. By the year 2030, nearly 150 million Americans will have some type of chronic illness, a 50% increase since 1995.

Persons with chronic illnesses often ignore the illness, self-medicate, and/or unconsciously adapt to the symptoms of the disease, especially if those symptoms are relatively mild (Charmaz, 1991). Most symptoms associated with a chronic illness are treated without the assistance of medical experts: It is only when these symptoms become persistent, disruptive, visible, and difficult to explain that physician care is sought (Mechanic, 1995). The diagnosis of chronic illness can generate intense emotional distress in patients and their families. This emotional distress is often manifested as feelings of extreme vulnerability, helplessness, and uncertainty over the future (Cohen, 1993). Depending on the nature and severity of the condition, persons living with a chronic illness can find the experience extremely challenging. Psychologically, people with a chronic illnesses experience a number of fears, such as keeping their body and

self-esteem intact, losing love, relationships, having the approval of others, and the associated pain and discomfort (Miller, 2000).

Coronary artery disease (CAD) is a chronic illness and in addition to cerebrovascular accidents and cancer is one of the leading causes of death in the elderly (Weitz, 2001). Heart disease and cancer are the leading causes of death within this population, with death rates varying by age, sex, and race. Currently, approximately 80 % of seniors have at least one chronic health condition, and 50 % have at least two chronic health conditions (National Institute on Aging, 2006).

This rise of chronic illness in the general population has challenged families in providing care for their sick and/or disabled members. There are associated caregiving challenges linked to the variables of a chronic illness including the onset of the illness, the course, the degree of incapacitation and the outcomes (Rolland, 1994). The difficulty with CAD is that there is such a wide variation for each of these variables. CAD may have a gradual onset with slow acceleration of symptoms versus an acute onset associated with a myocardial infarction. The course may be a progressive one interrupted with acute anginal episodes. This onset and course experience has a direct effect on the degree of incapacitation and achievement of outcomes for the affected individual. In addition the stress and burden associated with chronic illness for the caregiver. Postoperative CABG patients experience the reality of the chronicity of their illness. At times it is delayed as they and their caregivers focus on recovery from the immediate surgical event.

Insights into those individuals who undergo a CABG operation suggest that the surgery is regarded as a significant major life event. The participants in one study

indicated that the procedure was like the removal of a death sentence and a means to an addition of 'years to life and life to years'. Undergoing the operation was described by 'enormity of the experience' and 'the importance of lay support'. Research has also suggested that at times there are unrealistic expectations linked to the benefits of CABG such as eradication of the underlying CAD and the need for further medical intervention (Lindsay, Smith, Hanlon, & Wheatley, 2000).

Expectations of Surgery and Chronic Illness

Atherosclerosis, an underlying etiology to CAD, requires long-term, continuous medical interventions and lifestyle modifications. Both patients and informal caregivers tend to delay acknowledging this reality, regardless of surgical revascularization. Procedures, modern medical interventions and technologies have extended the lives of chronically ill persons but may not result in complete recovery. The fact that surgery may not remove all symptoms increases the responsibility of families for caring for the individual post surgery and over time. In addition, the healthcare system often fails in providing patients and families with needed resources following surgery. In a study following CABG patients one year post surgery, postoperatively as compared to preoperative interventions, there was statin prescribing, but less widespread, less effective and poorly applied postoperative secondary prevention measures by healthcare providers (Belcher et al., 2002).

As recovery from surgery progresses from the acute phase to a more long term phase, there is a shift to focusing on the management of existing chronic illnesses. Although most patients report improved health and well-being after coronary artery

bypass operation, many have described their recovery and rehabilitation as a complex process, with both short and long term effects (Tolmie, Lindsay, & Belcher, 2006), and one of that is highly variable (Dantas, Motzer, & Ciol, 2002).

Postoperative CABG Symptoms after Recovery from Surgery

Individuals who report angina at the time of follow-up, symptoms of heart failure equivalent to New York Heart Association (NYHA) classes II to IV, and comorbidities such as diabetes and hypertension often have a poorer health and quality of life post surgery. For both men and women without angina or heart failure at follow-up, health related quality of life was no different from that of the general population (Bradshaw, Jamrozik, Gilfillan, & Thompson, 2006). Some recovering CABG patients, women in particular, reported facing the challenge of recognizing and modifying health behaviors in a social context that compromised optimal recovery (Angus, 1996).

There is evidence that individuals who avoid acknowledging the chronicity of CAD demonstrated poorer self-rated health, increased post-traumatic stress disorder (PTSD) symptomatology, negative illness representation and increased depression (Oxlad & Wade, 2006). Researchers suggest that there may be unresolved issues and unanswered questions regarding transitions and the return to a preoperative lifestyle (Gilliss & Belza, 1992) for these individuals that affect lifestyle after surgery. These concerns may include resumption of social and sexual activities (Gilliss & Rankin, 1988), resumption of familial roles (Plach & Heidrich, 2002), fear of a new myocardial infarction (Lukkarinen & Kyngas, 2003), readmission to the hospital, ongoing anxiety, stress, due to

relationship, financial and role change (Jaarsma, Kastermans, Dassen, & Philipsen, 1995). For the caregiver, these responses may sustain the length of caregiving.

Family Caregiving

As postoperative recovery becomes a reality within the home setting, it is essential for nursing and the individuals who assume the informal family caregiving role to have a true understanding of just what the experience is about. Family caregivers comprise the overwhelming majority of homecare services in the U.S., approximately 80% (AHRQ, 2004). Family caregivers who provide care for 36 or more hours each week, are more likely than non-caregivers to experience symptoms of depression or anxiety. Spouses may experience these symptoms at the rate six times higher; for those caring for a parent, the rate is twice as high (Cannuscio et al., 2002). Educational interventional studies with caregiving dyads coping with osteoarthritis (Martire et al., 2003), dependent care recipients in the community (Greenberger & Litwin, 2003) and caregivers of individuals with dementia (Gerdner, Buckwalter, & Reed, 2002) have demonstrated that when increased skill and psychosocial support is given to these caregivers, there was significant decrease in anxiety, uncertainty, depression and caregiver burden.

Defining Caregiving

There are many ways to classify caregiving including frequency (intermittent versus continuous) of caregiving; the nature (routine versus crisis) of the experience; skill set (specialized versus nonspecialized); and illness trajectory (Gilliss & Belza, 1992; Perlick, Clarkin, & Sirey, 1995). Caregiving may be categorized from the perspective of

intergenerational, interspousal, or other intrafamilial aid using the criterion of dependence on another person for any activity essential for daily living (Walker, Acock, Bowman, & Li, 1996).

Caregiving has been described as distinct phases, with the decision making processes and the purposes of care defined or described within each phase. In a study focusing on decision making associated with providing care for elderly family members, Caron & Bowers (2003) defined a first phase of caregiving as interrelational, focusing on protecting and maintaining the care recipient self and the previous caregiver/care recipient relationship. The second care phase was viewed as pragmatic and focused on providing and assuring comfort and quality of care, as well as minimizing costs. Caregiver transition occurred between the phases, was subtle, nonlinear, and appeared to occur as the caregiver experienced increasing difficulty maintaining and protecting the relationship with the care recipient. During the initial interrelational phase, the focus was on the care recipient, with a loss in caregiver identity. The caregiver/care recipient relationship was well maintained until the shift in focus occurred from care recipient back to caregiver. The study indicated that unless both individuals recognize these shifts and alterations, the caregiving process was jeopardized (Caron & Bowers, 2003).

Although there has been a well-developed body of research on family caregiving in the past decades, there appeared to be no clear, concise definition of family caregiving used in the literature (Walker et al., 1995). Family caregiving has been defined as the provision of direct or managed services by one family member to another (Archbold & Stewart, 1986). It has also been viewed as an essential element in the family health

continuum with an individual's family as the most social context within which illness occurs and is resolved (Litman, 1974). Other definitions have represented caregiving as occurring when one or more family members aid or assist other family members beyond what is required as part of normal, everyday life (Walker et al, 1995; Biegel, 1991) or when caregiving emphasizes nonordinary help provided for persons who are unable to take care of themselves as a result of failing abilities and resources. lia

Despite the search for a concise definition, family caregiving is a phenomenon that that is multidimensional and highly varied from one family unit to another. In her classic article on caregiving, Archbold (1979) found "Stress, personal and interactional response to caregiving, lifestyle changes, decision making within families and the provision of various supports are key areas in understanding the caregiving experience" (p. 61). Family caregiving may be experienced unexpectedly if acute illness or recovery from a surgical procedure is involved. The need for family caregiving may be sudden and range from minimal to total care and may last for years. Because of changes in healthcare delivery, the aging population and the increased chronic illness, families and friends are increasingly finding themselves in the position of caring or loved ones at home.

It is critical to remember that family caregiving is an interactive relationship that has its beginnings prior to the onset of illness and does not happen in a vacuum (Conger & Marshall, 1998). Archbold researched mutuality and preparedness in caregiving and has been a critical force in the evaluation of caregiver role strain and the formulation of appropriate interventions (Archbold, Stewart, Greenlick, & Harvath, 1990).

One study, controlled for variables considered predictive for caregiver role strain (gender, spouse, cognitive impairment, functional impairment, amount of direct care) found that mutuality between the caregiver and the care recipient along with preparedness for caregiving, were associated with lower levels of caregiver roles strain, for some but not all aspects of strain. Specifically, the study showed that there was lowered strain from direct care, decreased tension between the caregiver and care recipient and less global strain with greater mutuality and preparedness. Archbold et al (1990) emphasized that the magnitude of variance in many aspects of caregiver role strain can be explained by mutuality and advised that nurses include the quality of the family caregiver's relationship to the care recipient in their assessment of an individual. This research emphasized that nursing interventions, designed to improve the caregiver preparedness, were needed especially following the care recipient's hospitalization.

Within this research, a positive relationship between a caregiver and care recipient was found to result in less strain in the caregiving experience as the caregiver finds the caregiving inherently meaningful. Conversely, when low levels of mutuality or less positive relationship between the caregiver and the care recipient are present, it may lead to a negative impact on the caregiving experience.

Dimensions of Caregiving

There are multiple dimensions of family caregiving that have been researched and addressed in the literature. These include caregiver burden, role strain, skill and stress.

Caregiver burden. In the 21st century, with changing trends in family life, demographics and illness trajectory, caregiver burden continues to be of great interest. Although the early research into caregiver burden focused on the elderly, particularly those with dementia (Zarit, Reever, & Bach-Peterson, 1980) more current research has expanded the investigation of burden across populations and illnesses (Edwards & Scheetz, 2002; Schott-Baer & Fisher, 1999; Rubio, Berg-Weber & Parnell, 2001; Deeken, Taylor, Mangan, Yabroff, Ingham, 2003; Schumacher et al, 2008).

With increased interest in caregiver research, involving processes as in cardiac disease (Bull, 1992) cancer (Bakas, Lewis, & Parsons, 2001), neurological disorders (Edwards & Scheetz, 2002), terminal illness (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Tilden, Tolle, Drach, & Perrin, 2004; Wrubel, Richards, Folkman, & Acree, 2001) and depression (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; Rubio, Berg-Weger, Tebb, & Parnell, 2001), there has been a renewed recognition in the variability of factors that affect caregiver burden. These factors include the level and type of demand, trajectory of an illness, objective stressors of illness severity, prior hospitalization, length of recovery period, amount of patient change or distress, suddenness of onset (Biegel, Sales, & Schulz, 1991). In addition, studies have shown that the transition from hospital to home, considered an enormously stressful period for family caregivers, is a key time in one's perception of burden (Bull, 1992). Caregiver burden may also occur as the tasks involved in caregiving emerge and the impact of the caregiving experience on the caregiver is realized (DiBartolo & Soeken, 2003).

Caregiving is less burdensome when there is smooth transition, the care receiver is deemed as worthy and the caregiver is a part of the immediate family, the majority of care receivers have not relinquished all their family roles, relationships, and life activities, but rather continue to participate in and make vital contributions to their families and communities (Call, Finch, Huck, & Kane, 1999). Studies have reported that caregiver burden is a better predictor of caregiving outcomes than the care recipient's functional status (Greenberger & Litwin, 2003). Despite the fact that studies link caregiving burden with the individuality of the caregiver, the caregiver's ability to cope with the experience of caring for a family member affected by an illness or impairment (Perlick et al., 1995) has principally measured caregiver burden using quantitative methods.

Over the years, many instruments have been developed to measure caregiver burden. They include the Caregiver Strain Index (Robinson, 1983), Cost of Care Index (Kosberg & Cairl, 1986), Caregiver Burden Measures (Siegel, Raveis, Houts, & Mor, 1991), The Burden Interview (Zarit et al., 1980), Caregiver Burden (Stull, Koslosk, & Kercher, 1994), and Caregiver Burden Inventory (Novak & Guest, 1989). These measures have been used in multiple investigations. The Burden Interview (Zarit et al., 1980) and the Caregiver Strain Index (Robinson, 1983) appear most frequently in the caregiver burden literature.

Caregiver Skills. The skills required of family caregivers have grown in complexity over the years. Caregivers are expected to provide increasingly complex care to their family members. Family caregiver skill has been defined as “the ability to engage

effectively and smoothly in nine core caregiving processes” (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000, p.194). These skill sets include: monitoring, interpreting, making decisions, taking action, making adjustments, accessing resources, providing hands-on care, working together with the ill person and negotiating the health care system. The knowledge needed to address this increasingly complex skill set calls for nursing to investigate this phenomenon and develop interventions to assist these caregivers providing these services.

Schumacher, Stewart & Archbold (1998) reported that providing care well is important to caregivers and caregiving competency, knowledge, and skills are often a central concern for new caregivers. The difference between knowing a skill and knowing how to perform a skill has a profound effect on the caregiver’s experience. Caregiving skills go beyond information acquisition or knowledge building. These skills are acquired through practice over a period of time and result in a variation within the of caregiver’s expertise.

Skilled caregivers were reported to have personal characteristics and behaviors that were different than the less skilled. In addition, changes over time in providing care affected the development of caregiving skill and abilities. The study stated that the dimensions of caregiving could be both stable and changeable and the caregivers’ ability to continue in the caregiver role is individualized. The caregiver’s experience was influenced by the blend of previous skill, the caregiver’s ability to integrate knowledge about the care recipient including his or her identity, concerns and personal history into the experience and that caregiving skills developed over time (Schumacher et al,1998).

The authors' conclusions supported individuation of interventions for the caregivers and called for further research to uncover the development of caregiving patterns as well.

Study findings also stressed that health outcomes of aged or ill people are to some extent dependent upon adequate care by family members and that care receivers feel vulnerable when care is not provided.

Skilled caregivers can experience negative attitudes about caregiving at one time or another, but find that over time there is a lessening in negativity with the development of more positive attitudes about the caregiving process (Farran et al, 2004). Individuals who are more skilled in the caregiving process reportedly have an easier time in dealing with and making an effort to be flexible with the ensuing life changes (Farran et al, 2004). This can be accomplished by learning to set realistic expectations, focusing on the process rather than the outcome, and maintaining a balance between developing skills that responded to care recipient needs and those that provided for self care.

In a study involving caregivers of individuals with Alzheimer's disease, there was a distinct difference between the skilled and less skilled caregivers. Namely, the skilled caregivers were more likely to accept and acknowledge change, balance responsibilities by capitalizing on own and others' strengths and being able to negotiate, be flexible, creative and acknowledge care recipient's remaining strengths, know when to draw the line and seek outside help; and attempted to integrate self care into their lives (Farran et al, 2004).

Caregiver Dyad. In studies focusing on caregiving immediately after discharge from the hospital, few investigations focused on the interactions between the caregiving

dyad (the caregiver and care recipient) or the processes used to create the caregiving dyad. Existing research pointed to a process that occurs as an individual assumes the role of caregiver. These investigations identify factors that may contribute to the success of role acquisition and include the family resources, care recipient's illness trajectory, quality of relationship between the caregiver and care recipient, economic resources, level of problem solving skills, previous experience with crises handling, the onset and severity of illness and functional decline of the care recipient (Shyu, 2000).

Shyu (2000) focused on role tuning as the transitional process used by these caregivers and care recipient to achieve a harmonious pattern of caregiving and care receiving after leaving the hospital. The study indicated that the process began prior to discharge from the hospital as the individual prepared to assume the role of caregiver and address the unfamiliarity and uncertainty associated with the transfer of information regarding discharge. The caregiving dyad subsequently transitioned into their roles as caregiver and care receiver through role negotiation as they strove for a level of stable pattern of caregiving. Once back in their own familiar environment, they began to address their new roles and new realities. The research supported that the dyad may have disparate expectations of each other producing conflict and emotional reactions, reorganizations of schedules and reprioritizing. In what Shyu considered the third stage of role tuning, role settling, the caregiver and care recipient are able to settle into a stable pattern of caregiving interaction. This last transition may be subtle and although it leaves the dyad in a pattern of interaction that is harmonious, the dyad remains prepared for emergent situations.

An investigation that focused on dyadic identity of 60 informal family caregivers and care recipients using respite services revealed three categorizations of dyadic identity and rules needed to negotiate actions. The three types of dyadic identities included the complete and mutually accepted immersion by both parties' identities into dyadic caregiving and care receiving; the retention of personal identities while also accepting the caregiver or care receiver role; and the rejection of the caregiver or care receiver role by one or both parties. Study findings indicated that failure to agree upon the mutual definition of the dyad or to act upon negotiated rules based on the definition resulted in strain and disorganization of the care process (Coeling, Biordi, & Theis, 2003).

Findings from a qualitative study involving caregivers of extremely elderly (80+) relatives or friends stressed the importance of understanding how informal caregivers perceive the meaning, purpose and goals of caregiving (Aberg et al., 2004). Results indicated that the overall goal for the caregivers was to provide life satisfaction in the care recipient at the highest level. There were two major themes extracted from this research: caregiver categorization and life satisfaction. The researchers delineated three caregiver categories. First, social-emotional caregiving that dealt with the support of the continuity of self-image; secondly, proxy caregiving involving the protection against physical and emotional harm; thirdly, instrumental care which was the protection of health status and integrity. Life satisfaction was established as directly related to the continuity of the care recipient sense of self. The overall message from this research was that the caregiver categorizations have a profound influence on how the caregiver viewed

care recipient life satisfaction. This study underscored the value of informal caregiving and supported the caregiving interaction as balanced by reciprocity.

Caregiver Burden and Support. Resources and support systems for the elderly caregiver are essential to decrease his or her caregiver burden. Loneliness and access to a small or non-existent network are significantly associated with poor quality of life among caregivers. The research supports a significant association between loneliness, weak social network and low mental quality of life (Ekwall, Sivberg, & Hallberg, 2005). Although the burden of caregiving is not easily reduced, when caregiver resources are strengthened, particularly by a health care provider, there may be some relief for the caregiver. The burden and stress of caregiving do not necessarily have to be a negative experience. Quality caregiving can exist in the presence of a caregiver's perception of burden. It is essential, particularly, with an increasing dependent older population and the increase in chronic illnesses, that personal and social resources be more readily available for caregivers (Greenberger & Litwin, 2003).

Spousal Caregiving

As stressful as family caregiving is, those informal caregivers who are spouses are at an even higher risk for negative outcomes. Elderly spousal caregivers with a personal history of chronic illness, and who are experiencing caregiving related stress, have a 63% higher mortality rate than their non-caregiving peers (Schulz & Beach, 1999). Researchers have suggested that the combination of loss, prolonged distress, the physical demands of caregiving, and biological vulnerabilities of older caregivers may

compromise physiological functioning and increase caregivers' risk for physical health problems and increased mortality.

Schulz & Beach (1999) examined the relationship between caregiving demands of older spousal caregivers and four-year all-cause mortality rate. This was based on level of caregiving where the spouse was not disabled; the spouse was disabled and not helping; the spouse was disabled and helping with no strain reported; or the spouse was disabled and helping with mental or emotional strain reported. After adjusting for sociodemographic factors, prevalent disease, and subclinical cardiovascular disease, participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than noncaregiving controls. Participants who were providing care but not experiencing strain and those with a disabled spouse who were not providing care did not have elevated adjusted mortality rates relative to the noncaregiving controls. The study suggests that being a caregiver and experiencing mental or emotional strain, is an independent risk factor for mortality among elderly spousal caregivers and that caregivers who report strain associated with caregiving are more likely to die than noncaregiving controls (Schulz & Beach, 1999).

Potentially harmful caregiver behavior is more likely in spouse caregiving situations, when care recipients have greater needs for care, when caregivers are elderly, more cognitively impaired, have more physical symptoms, and are at risk for clinical depression (Beach et al., 2005). In general, older people in the United States are healthier than in the past, with lower rates of disability. Still, a significant proportion suffers from

multiple health problems and chronic disease resulting in death rates that have not changed dramatically over the years.

There are also reported gender differences in spousal caregiver stress. These differences may be related to both problem and helping behaviors of the care recipient. Helping behaviors had a moderating effect on the relationship between care-recipient problem behaviors and stress for caregiving husbands, but not for caregiving wives (Ingersoll-Dayton & Raschick, 2004). In an investigation comparing caregiving wives to noncaregiving wives there was no significant difference in self-reported closeness to their husbands or change in shared values, but there was significantly less reciprocity in their marriages, fewer shared pleasurable activities with their husbands and a lowered sense of resilience for caregiving wives. The study questioned if the wives' ability to maintain their perception of some degree of emotional intimacy was a critical factor in maintaining the caregiving role (Gallagher-Thompson et al, 2001).

There is some indication that the definition of spousal caregiving had a direct relation with the emotional health of the caregiver. These definitions ranged from engaged to distanced. In this study, the varying degrees of caregiver involvement were directly related to the caregiver and recipient's ability to immerse into a dyadic identity or to resist relinquishing the identity of self (Wrubel et al., 2001).

Family Caregiving with the Cardiac Surgery Patient

A review of the existing literature regarding family caregiving and patients experiencing cardiac surgery yielded seven qualitative studies and fourteen quantitative studies. In quantitative studies, the most frequently measured outcomes included family

function and health (Astedt-Kurki, Lehti, Tarkka, & Paavilainen, 2004; Monahan, Kohman, & Coleman, 1996; Rantanen, Kaunonen, Astedt-Kurki, & Tarkka, 2004), knowledge (Eales, Noakes, Stewart, & Becker, 2005; Leske, 1993), stress and burden (Astedt-Kurki et al., 2004; Davies, 2000; Leske & Pelczynski, 1999; O'Farrell, Murray, & Holtz, 2000; Stolarik et al., 2000), social support (Astedt-Kurki, 2004; O'Farrell, 2000; (Ivarsson, Sjoberg, & Larsson, 2005; Leske & Pelczynski, 1999; O'Farrell, Murray, & Holtz, 2000; Stolarik, Lindsay, Sherrard, & Woodend, 2000), gender differences (Rankin, 1990) and spousal quality of life (Artinian & Hayes, 1992).

The qualitative studies uncovered themes focusing on uncertainty, monitoring the recovering spouse (Knoll & Johnson, 2000), managing illness and everyday family life (Davies, 2000; Knoll & Johnson, 2000), emotional reactions to caregiving and the effect on their lives (Ganske, 2006), anxiety and stress (Theobald & McMurray, 2004), the need for information (Gillis & Belza, 1992), caregiver emotions in the early postoperative period (Cozac, 1988) and concerns and demand of symptom management, physical care requirement and medications (Artinian & Duggan, 1993).

Studies that centered on the family after a member had coronary artery bypass grafting discussed how the event could immobilize a family. They reported that the first days of post hospitalization were the most difficult and frightening, accompanied by feelings of being unprepared to deal with the stress and anxiety of the situation. These emotions were often initiated as caregivers awaited their relatives' surgery. In a study involving 23 next-of-kin of patients awaiting a relative's elective CABG surgery, an assessment was conducted using a qualitative interview schedule with internal and

external factors identified as contributing to being able to provide support to the preoperative patient. Positive internal factors were linked with finding strength, whereas negative factors were associated with uncomfortable feelings. Positive external factors were also associated with participating in care and receiving attention, whereas negative factors were associated with dissatisfaction with the health-care organization and failing social network (Ivarsson et al., 2005).

Family support was found to be vital to optimal patient outcomes in an early discharge program (Leske & Pelczynski, 1999). In this project, caregivers were helped to understand that it was not unusual to feel unprepared for the responsibility of the recently discharged individual. Caregiver satisfaction with preparation for discharge in a decreased length of stay cardiac surgery program was examined. Responses were obtained from caregivers (N = 53) of cardiac surgery patients discharged on postoperative day four or five. These responses were analyzed with regard to caregiver satisfaction and preparedness for discharge, preference for a longer hospitalization, benefit of an earlier discharge, as well as patient care expectations. Results indicated that the majority of caregivers preferred earlier discharge but did not feel prepared for the responsibility of patient care. The study recommended a shared link in communication between the hospital and the home setting be established in an effort to promote both caregiver and care recipient well being (Leske & Pelczynski, 1999).

Studies focusing on the spousal relationship and caregiver burden in the postoperative CABG population reported that if there were low levels of marital satisfaction preoperatively, caregiver burden was reported as higher (Rankin, 1988) with

lower satisfaction and communication (Monahan, Kohman & Coleman, 1996). In addition, known depression in spousal caregivers was the strongest predictor for depression associated with caregiving (Halm, 2008). Research also found that this depression may remain higher than baseline for up to three months after assuming the caregiver role (Rankin, 1988; Lenz & Perkins, 2000). In research that focused on these spousal caregivers at one year after surgery, findings indicated that a spousal caregiver's quality of life was directly related to their spouse's objective physical health, the spouse's subjective perception of his or her own health and affirmative support (Artinian & Hayes, 1992).

Family Caregiver Uncertainty and Recovery from CABG

Uncertainty that occurs for spousal caregivers as they live through this illness experience and recovery period is intense. Caregivers reported stress and vulnerability, put their lives on hold and indicated that the caregiving affects all elements of their lives (Knoll & Johnson, 2000). Theobald (1999) indicated that this uncertainty has its origin in the lack of ongoing information and the anxiety that pervades the care of a loved one. A further study discussed the presence of ongoing anxiety and stress due to relationship adjustment, adaptation to the new caregiver role and the existence of financial difficulties during recovery from surgery. Caregivers viewed their futures as extremely uncertain. They discussed how critical support systems were and the need for guidance around assuming the caregiver role and strategies for monitoring patient progress (Theobald & McMurray, 2004). In addition, when comorbid conditions existed or post-operative complications occurred, caregiving became even more complicated due to increased

medical technology in the home, the ensuing duty, and lack of choice in decision making. In addition, caregivers often had an unrealistic expectation of their ability to care for the recovering patient challenging the role even further (Kneeshaw, Considine, & Jennings, 1999).

Gender and Caregiving

An understudied variable in the family caregiving of the postoperative cardiac surgical patient has been reported to be gender. Patterns of informal caregiving noted in the chronic care literature reported that in the short-term care of post-surgical cardiac patients, the burden of care-giving continues to rest predominantly on women (King & Koop, 1999). Two studies in particular, addressed this issue. The first discussed how a cardiac patient's gender affected the availability of home based care with higher availability to male patients (King & Koop, 1999). Further work by (King, 2000) indicated that 30% of male care-givers to female patients post CABG were reported to have a health problem of their own to manage while caring for the recovering patient. Male patients, less than 65 years of age, had higher social support scores than did a similar group of female and patients greater than 65 years of age. Findings suggested that the cardiac patient's sex affects the availability of home-based care. In addition, care-givers may themselves be patients in need of care.

A second study addressed levels of emotional support for female patients after cardiac surgery. The descriptive, prospective study used questionnaires focusing on biological variables, symptom status, functional status, general health perceptions and perceived quality of life. Results indicated that despite the fact that postoperative women

cardiac patients tend to have lower anxiety levels and greater levels of well being than before surgery, nearly 25% experience severe psychological distress as long as three months after surgery. The findings suggested that these women received less emotional support from their family caregivers after surgery than their male counter parts (Penckofer, Ferrans, Fink, Barrett, & Holm, 2005).

Family Caregiving and the CABG Recovery Trajectory

The literature reports a correlation between the caregiving role demands/concerns and the postoperative care recipient recovery trajectory that occurs in the first month after CABG surgery. Studying the recovery trajectory in this specific surgical population has important implications for family caregiving. Variables that have been studied within this theme are: intervening early in the discharge period (Davies, 2000), being aware of the timeframe for shifting of concerns (Hartford, 2005) and knowing that patterns of care present in the chronic care literature can also be applicable to the short-term, post-cardiac surgery population during recovery at home (King & Koop, 1999).

An investigation with spouses of patients undergoing cardiac rehabilitation after coronary artery bypasses grafting indicated that caregivers actually had a greater amount of stress than the patients. In this study, spousal caregivers needed to integrate the impact of the cardiac event on themselves and their relationship with the patient. The study acknowledged the influence that spouses had on the recovery period and showed that some caregivers were unable to have a positive influence on the recovery because of an inability to adjust to their own level of stress and uncertainty in caring for their spouse.

The authors call for further research as to the nature of this stress and the effects on the recovery pattern (O'Farrell et al., 2000).

Caregivers of the patient after CABG surgery also focused on the concerns and caregivers' demands for symptom management, physical care, and medications within the context of the early recovery trajectory and the subsequent concerns and demands that occurred on a week to week basis. Findings suggested potential misunderstanding regarding the amount of work in caregiving and how that amount varies throughout the first four weeks of recovery at home. Emotional reactions to caregiving included frustration and fear and physical reactions included exhaustion and illness (Artinian & Duggan, 1993). Another qualitative study focusing on participants caring for the elderly (greater than 80 years old) recovering CABG patient offered insight on how emotional and physical reactions became more positive as the weeks out of the hospital increased. They also described how interactions with formal caregivers prior to discharge had a direct effect on how prepared they felt to assume the caregiver role (Ganske, 2006).

Early discharge appears to be viewed more positively by the patients than their caregivers, who often express fear of the inability to handle both the physical and emotional needs of the care recipient (Engelmann et al., 1994; Moore & Dolansky, 2001). Spouses of CABG patients reported greater levels of psychological distress than the patients, and the spouses who assume the care giving responsibility often express need for support. Spousal caregivers describe needing the chance to absorb the impact of cardiac surgery on a loved one and the ensuing changes that affect their future relationship. In addition, caregivers found themselves under an immense pressure to

assume the responsibility for medication distribution, pain control, and symptom management of an individual who has just experienced major surgery (Jaarsma, Kastermans, Dassen & Philipsen, 1995).

In a study focusing on caregiver satisfaction with discharge, it was found that caregiver satisfaction with the timing of discharge tended to be higher at one week post discharge rather than at six weeks post discharge. This increasing dissatisfaction with the time of discharge may be due to either naïveté or the caregiver not being sufficiently prepared for the ongoing care of his or her spouse during recovery. Decreased satisfaction with the timing of caregiving could also reflect spousal concern about the potential long-term, unending work and the recognition of the need for a break from caregiving. After the initial recovery, managing the illness and everyday family life were main priorities (Davies, 2000).

Knoll & Johnson (2000) focused on the process and the effects of informal caregiving for cardiac patient postoperatively. Findings indicated three processes of caring emerged from the data. First, vigilance and monitoring of the patient, second keeping track of things such as medications, pain management, and thirdly the directing activities back to “normal”. Caregivers stressed the need for nursing interaction as they continued to be unsure what to expect and what was normal versus abnormal. The effects of caregiving were reported as feelings of stress and fatigue, an increased sense of vulnerability and the feeling of putting one’s life on hold. The study proposed that process of caregiving along with its effect, may have a detrimental consequence on the caregiver’s own health. The stressors associated with caregiving that affect the

postoperative patient affect also the caregiver as he or she attempts to deal with the moodiness and worries of the care recipient. This, in addition to the carer's own stress regarding treatment, recovery and prognosis, long term role and lifestyle changes and financial concerns can further compromise the caregiving experience.

Caregivers reported that they were reluctant to disclose their own concerns for fear of further distressing the patient, thereby increasing their own anxiety (Lindsay, Smith, Hanlon, & Wheatley, 2000). Further research showed that the informal caregiving had an enormous impact on the health outcomes of care recipients and spouses who become caregivers to those individuals following cardiac surgery. These caregivers often stated they felt unprepared to deal with the stress and anxiety surrounding their spouses' health event (Leske & Pelczynski, 1999).

Several significant themes emerged in the extant literature on family caregiving and the recovering CABG patient that have major implications for this caregiving population and nursing. The first is the need to support family function in the midst of the illness crisis. Support may be viewed as informational (Eales et al., 2005), psychological (Hartford, 2005), and emotional (Stolarik, 2000). There is an emphasis placed on knowing the families of these patients recovering cardiac surgery and making an effort to support them in everyday practice (Astedt-Kurki et al., 2004). Supporting the family was found to be not only essential for the families' health, but also vital to optimizing patient outcomes, particularly in the setting of early discharge to home (Leske & Pelczynski, 1999). Rantanen et al. (2004) acknowledge the importance of family caregivers during

the recovery process and called for nursing support and care of the entire family, not just the recovering patient.

The literature also acknowledges the need for family assessment. Davies (2000) stated that a needs assessment could be helpful in targeting caregiver support early in the recovery period. Kneeshaw et al. (1999) discussed how mutuality scores between caregiver and care recipients were lower at three months after discharge than at the time of discharge indicating an increased level of family stress. The authors recommend assessing situations and directing nursing interventions during the discharge planning period to support those individuals even after the acute period of recovery was completed. An additional study encouraged caregivers to be screened for psychological distress, marital concerns and family issues prior to discharge and through the recovery process (O'Farrell et al., 2000).

Family Caregiving and Vulnerability

Vulnerability is defined as feelings of being exposed to emotional hurt, being taken advantage of or abused; being fragile, weak, or susceptible to emotional pain and suffering; being trapped or imprisoned in a situation where your feelings and rights are ignored. Care burden, restricted activities, fear, insecurity, loneliness, facing death, lack of emotional, practical and information-related support were identified from the data as factors having the potential to increase a caregiver's vulnerability (Fulmer et al., 2005). A family's level of vulnerability is determined by the stressor event, the family's perception of the event, and the family's resources for dealing with the event all help to determine

how vulnerable a family is and its ability to prevent the stressor from creating a crisis (McCubbin et al., 1980).

The family is considered to be the most important contextual influence in human growth and development and is the link between the individual and society (Murphy, 1986). In addition, the home environment provides a rich context in which to look at situational and developmental stressors that affect the family structure and function (Moriarty, 1990). Nurse researchers who interact with families during this potential time of crisis are in a unique position to evaluate how families benefit or not from the caregiving experience. There is a need for research that adds to our knowledge of family functioning and structure and contributes family theories to science (Juarez, Ferrell, & Rhiner, 2004).

During recovery from CABG surgery, postoperative complications as well as pre-existing comorbidities can produce a vulnerable group of patients with the likelihood of less than optimal recovery. In addition, the uncertainty of the course of CAD may produce increased sense of vulnerability for both the caregiver and the care recipient. One study found that 80% of spouses of CABG patients were fearful of either having a chronic illness or their spouses dying (Monahan et al., 1996).

The literature supported the role nurses play in understanding and responding to the vulnerable position (illness, recovery, grief) of patients and families often unable to recognize or divulge their needs (Niven, 2003). In a phenomenological study of patients' experiences after cardiac surgery, researchers reported a prominent feeling of fragility associated with uncertainty, vulnerability, reliance and gratitude (Karlsson, Johansson, &

Lidell, 2005). Social isolation that accompanies work cessation in order to care for a family member has also been shown to significantly correlate with caregiver vulnerability (Pohl, Collins, & Given, 1995). Furthermore, it is speculated that a poor premorbid relationship makes caregiving more stressful because of a greater difficulty in performing the caregiving role. The premorbid relationship or high loss of intimacy can act as a vulnerability factor, predisposing the caregiver to depression. (Morris, Morris, & Britton, 1988).

Interventions Studies: Family Caregivers and the CABG Patient

Nursing interventions related to caregiving in other populations have proven successful. A review of the published findings from randomized clinical trials including populations of very low birth-weight (VLBW) infants (Brooten, 2002); women with unplanned cesarean births (Brooten, 1994); high risk pregnancies (York et al, 1997); hysterectomy surgery (Hollingworth & Cohen, 2000); elders with cardiac medical and surgical diagnoses (Naylor et al, 1999) demonstrated that APN interventions consistently resulted in improved patient outcomes and reduced health care costs across populations. Those individuals with APN providers were rehospitalized for less time at less cost, reflecting early detection and intervention (Brooten et al., 2002).

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Further research by (Brooten, Youngblut, Deatrick, Naylor, & York, 2003), stressed that the dose of APN time and patient/family contacts makes a difference in improving patient outcomes and reducing health care costs. Findings from this study emphasized the skills needed by APNs in providing transitional care. These included

well-developed skills in assessing, teaching, counseling, communicating, collaborating, knowing health behaviors, negotiating systems, and having condition-specific knowledge about different patient problems (Brooten et al., 2003).

In an investigation involving APNs given specialized training emphasizing educational and behavioral caregiving strategies in the home, significant care savings in care overall were reported. The strategies used addressed high risk older adults and their caregivers' unique learning needs throughout an episode of acute illness. The APNs coordinated the care provided to these individuals by the physicians, pharmacists, social workers, RNs, and other health team members involved in their care. Although the total costs of providing this level of care for patients in the APN group was nearly double that provided to patients receiving routine care, the increase more than offset cost savings with fewer hospital readmissions. The higher level of care actually demonstrated a 37% savings over a 12 month period (Naylor, 1999).

Intervention Studies and CABG Population

A review of the extant literature revealed 23 nursing intervention studies focusing on the CABG population. Only three of these studies focused on family caregivers of the postoperative CABG patient. The foci of the remaining studies addressed: symptom management (Moore & Dolansky, 2001; Tranmer & Parry, 2004; Williamson, 1992; Zimmerman, Barnason, Nieveen, & Schmaderer, 2004); lifestyle changes to decrease cardiac risk factors (Allen, 1996; Froelicher & Christopherson, 2000; Hajek, Taylor, & Mills, 2002; Moore, 1997); support for those living alone (Rankin, Butzlaff, Carroll, & Reedy, 2005); subjective health (Beckie, 1989; Hartford, Wong, & Zakaria, 2002;

Okkonen & Vanhanen, 2006); predictors of complications (Hassan, Smith, & Engel, 2006); functional and health outcomes (Barnason et al., 2000; Hiltunen et al., 2005; Moore & Dolansky, 2001; Naylor & McCauley, 1999; Savage & Grap, 1999; Speziale et al., 2005; Watt-Watson et al., 2004); rehabilitation needs (Smith, Harkness, & Arthur, 2006); and community social support winder (Winder, Hiltunen, Sethares, & Butzlaff, 2004).

The first reviewed intervention study involving family caregivers used a staged, postoperative psycho-educational intervention for CABG patients and their family members and then evaluated the impact on patient and family outcomes (Lenz & Perkins, 2000). The hypothesis was that the individuals who received an experimental intervention would demonstrate improved levels of physical and psychological health outcomes, functional health outcomes, and greater satisfaction with care than those individuals who did not receive the intervention. The study enlisted 38 elective postoperative CABG patients/family members (19 experimental/19 control pairs).

Both the intervention and control group received the standard discharge information and home visit. Prior to discharge, the patient and family member dyad in the intervention group received a structured, individualized counseling session with a cardiac clinical nurse specialist (CNS) focusing on physical feelings and emotional adjustments of the patient after discharge and the family's role in the recovery process with strategies for handling potential conflicts. On the day after discharge and weekly for the next six weeks, then biweekly for the following six weeks, the patient and family member received phone calls from the CNS. The phone calls focused on instructional information

and, using a semi-structured format an assessment was done to identify any emotional issues. A group support session was held one month into the study, providing the participants with the opportunity to talk directly with a psychiatric CNS who specialized in group therapy. This investigation used a pretest-posttest design to measure physical health outcomes by an investigator using a checklist that identified commonly occurring symptoms and complications. Emotional health was measured by the Center for Epidemiologic Studies-Depression (CES-D) scale; functional health status was measured by the COOP chart and satisfaction with care was measured with the Patient Satisfaction Questionnaire.

Study findings reported that the experimental and control groups did not differ in emotional health, functional health status, or satisfaction and differences in the number of self-reported complications/symptoms were not in the predicted direction with the experimental group reporting greater incidence of complications/symptoms. Conclusions suggested the importance of including the influence of the home environment, the need to address the normalization of emotional aspect of recovery through repeated discussions with the investigators, and the need to examine the psychological histories or profiles of family caregivers and the marital satisfaction.

A second intervention study reported findings from a randomized controlled trial that evaluated the effectiveness of an information and telephone support to reduce anxiety in patients post coronary artery bypass graft surgery and in their partners (Hartford et al., 2002). The intervention included the use of standardized protocols regarding predefined postoperative issues and support from nurses, available 24 hours a day. The intervention

was initiated at the time of discharge and occurred during six nurse-initiated telephone calls (Days 1, 2, 4 and weeks 1, 4 and 7) over a seven week period. Levels of anxiety were measured with the Beck Anxiety Inventory. Participants (N=131) were patients who have undergone elective coronary artery bypass graft surgery along with their partners and their family caregiver.

Patients reported moderate to severe anxiety the day before discharge; however, anxiety scores were significantly lower in the treatment group than in the control group on day 2 at home but were not significantly different during the remainder of the study. Partners who assumed caregiving consistently had lower anxiety than patients. The caregiver treatment groups also demonstrated a more sustained decrease in anxiety at week two and three. Conclusions drawn from this study included the need to address the effects of returning to a familiar (home) environment on anxiety levels, the effects of female interviewer with a predominantly male patient sample, the inability of an individual to distinguish between true and masked anxiety, timing of the interventions and the lack of female patients versus caregivers (84% male patients in this study).

In a nursing intervention study involving family caregivers, the focus was on the spouses of 226 male and 70 female CABG patients (Mahler & Kulik, 2002). The intervention included delivery of videotaped information that included what to expect during recovery and expected spousal experience during the recovery process. Two videotapes were created, one labeled as “mastery” tape and the other as “coping”. The information in both tapes was delivered by a cardiothoracic nurse specialist and contained narratives from four postoperative CABG patients and their spouses. Participants

discussed in detail their experiences at the time of discharge from the hospital, one week and one, three and six months after discharge. The mastery videotape was carefully edited to present the couples as calm. In the videotape potential problems are not mentioned and the couples are portrayed as experiencing an uneventful, positive postoperative course. The coping tape presents couples who discuss concerns regarding hospital release. The couples are depicted as successfully coping with a variety of postoperative recovery issues. The cardiothoracic nurse specialist provided information regarding how to deal with these potential issues. The study sample was randomly assigned to view this optimistically slanted information tape, a tape that featured coping with more ups and downs of recovery or no tape at all.

Results indicated that women, whether as patients or as caregivers, were at elevated risk for a variety of negative outcomes, in particular emotional outcomes during the subsequent 6 months after surgery. Female patients whose spouses were exposed to the optimistic, mastery-tape had a lower level of negative outcomes than women whose spouses received only standard discharge preparation (post discharge issues requiring office visits and/or rehospitalization). The authors of this study concluded that there was a need for further research focusing on optimism and its effects on caregiving. If as this study suggested, men were generally less effective caregivers than women, the mastery videotape used may have met a greater need in the male caregivers and could result in a greater effect in female spouse recovery.

Health as Expanding Consciousness: A Framework for Studying Family Caregivers' Response to Postoperative CABG Patients

Theoretical Origins

It is helpful to understand the multiple theoretical origins for the Theory of Health as Expanding Consciousness. From Georg Hegel, Newman utilized the dialectical fusion of opposites in her fusion of disease and nondisease to create health (Witucki, 2002). Martha Rogers' theory, Science of Unitary Being, was a profound influence and her contribution can be found in Newman's focus on wholeness, pattern and unidirectionality. A critical difference between Rogers' and Newman's theories is the attribution of consciousness to all matter and energy (Sarter, 2004). David Bohm's Theory of Implicate Order supports Newman's concept of pattern in the universe as a whole and, in particular, health as a manifestation of the hidden pattern of person-environment. According to Bohm, there is an inseparability of the process and the content of thought. He believed the metaphysical ground of being is a multidimensional pattern, unseen, yet generating the explicate or seen world. In the theory of Implicate Order, Bohm stated that there was a need to drop the notion of the analysis of the world into separate but interacting parts; the emphasis should be on the undivided whole. Newman availed herself of that concept by stressing how important it was to see the human being as unitary and as continuous with the undivided wholeness of the universe (Newman, 2007). Bentov's Evolution of the Consciousness described the fusion of contrasting concepts into one. He believed that all opposites, once transcended and reconciled, produced an absolute consciousness. This concept was inherent in the ability

of a system to interact with the environment. For Newman, the highest level of consciousness is reached through transcendence (Witucki, 2002).

Other contributing theorists included Pierre Teilhard de Chardin who believed that evolution in its higher stages involved an expansion of consciousness and unity with the universe along with a consciousness and unity that persisted even after death, a key factor in Newman's work (Sarter, 2004). Ilya Prigogine's Theory of Dissipative Structure was foundational for the concept of how an event in an individual's life can cause disorder in an otherwise ordered existence necessitating a choice to move in a new direction to a higher level of consciousness (Newman, 1999).

One of the most influential individuals in the development of Health as Expanding Consciousness was Arthur Young and his Theory of Sequencing of Human Evolution. This theory proposed a sequence of seven stages which begin with total freedom and unrestricted choice, followed by a series of losses of freedom. These losses are followed by a choice point in an individual's life that permits the reversal of the losses of freedom, ending with total freedom and unrestricted choice. These stages are conceptualized as a V shape. The first stage is potential freedom and is followed by the binding stage which indicates a sacrifice of the individual for the collective. The third stage, centering, indicates a break with authority and development of the individual's self-consciousness and self-determination. The fourth stage is choice and is situated at the base of the "V" (See Figure 1). This stage depicts self awareness, inner growth and transformation. The individual has arrived at critical turning point where the "old rules" don't work anymore. The individual's task in life is to discover "new rules" and continue

to move through the next stage, decentering. This stage is characterized by an experience of unlimited growth and knowledge on how to build order against the trend of disorder. Newman stated that it is within the stages of choice and decentering that an individual moves on to higher levels of consciousness (Newman, 1999).

Newman drew a parallel between her theory and this staging of human evolution in support of her tenet that life is evolving in the direction of higher levels of consciousness. She incorporated her concepts of time, space, consciousness and movement into Health as Expanding Consciousness within Young's sequencing of human evolution as evidenced by the figure below. "Order and disorder maintain a fluctuating field that periodically transcends itself and shifts into a higher order of functioning; and that in humans this evolutionary process is facilitated by insight and involves a transcendence of the spatial-temporal self to a spiritual realm" (Newman, 1999, p. 43).

As Newman's theory evolved, she has recognized that nursing requires "a scientific paradigm that embraces a unitary, transformative perspective, one in which the living system is involved in a series of giant fluctuations of unpredictable transformations" (Newman, 1999, p.140). This shift that Newman called for comes to fruition through the unitary-transformative paradigm of nursing and more specifically

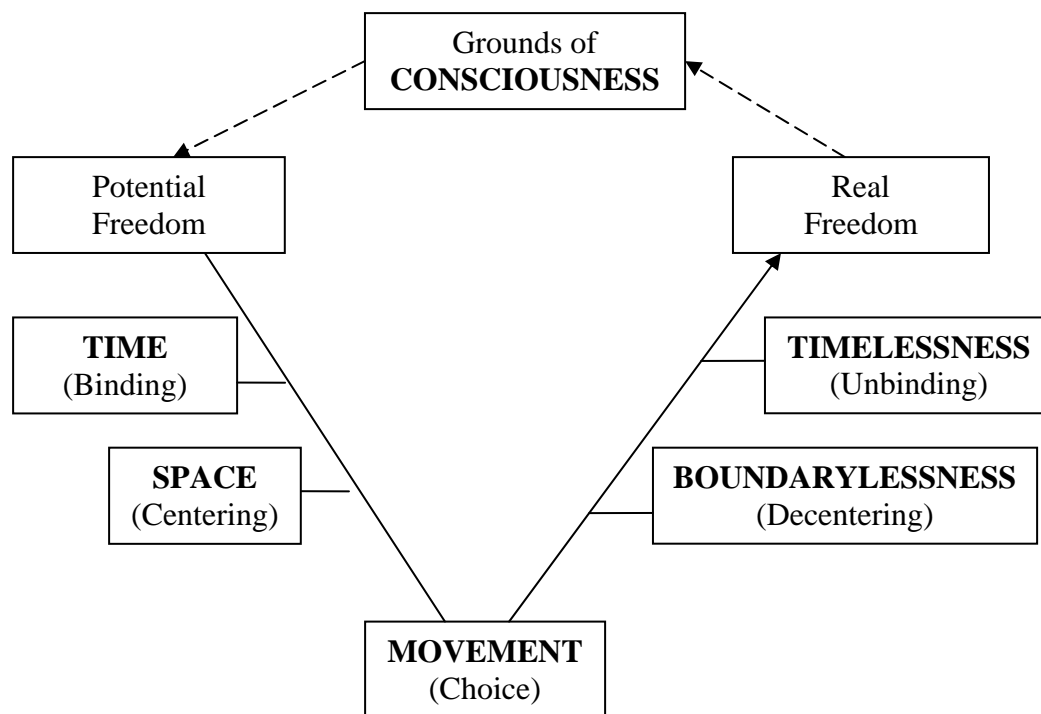


Figure 1. The interrelationship of Newman's basic concepts and Young's stages of evolution. From *A Developing Discipline: Selected Works of Margaret Newman* (p. 132), by Margaret A. Newman, 1995, New York: National League for Nursing.

within Health as Expanding Consciousness. Newman calls for a transformation from the treatment of symptoms to searching for pattern; a reexamination of disease and disruption that eliminates the negativity associated with these concepts and redefines them as essential parts of the self-organizing process of the expanding consciousness (Newman, 2007). Within this shift is a redefinition of the role of nursing from one that addresses the problems of disease to assisting individuals get in touch with their own pattern of expanding consciousness (Picard & Jones, 2005).

Health as Expanding Consciousness and the Role of Nursing

Newman believes that “the nature of nursing is a dynamic, relational process, and to understand it we must engage in the experience of it” (Newman, 1997, p. 36). She calls for a shift from the treatment of symptoms to searching for patterns; a reexamination of

disease and disruption that eliminates the negativity associated with these concepts and redefines them as essential parts of the self-organizing process of the expanding consciousness; and, a shift in the definition of the nursing role from one that addresses the problems of disease to assisting individuals get in touch with their own pattern of expanding consciousness (Newman, 1999).

The reflective nature of the nurse-client relationship facilitates this pattern recognition and allows the nurse to focus on the quality and connectedness of relationships. The nursing ideal is to be fully present to the client without judgments, goals or intervention strategies. It is being rather than doing; a partnership that involves respect and caring (Newman, 1999). With the recognition of pattern comes the potential for action and within that potential comes the possibility of transformation.

Nursing within this paradigm is considered a dynamic and relational process and “to understand it [nursing] we must engage in the experience of it; we must study the process of our relationship with our clients” (Newman, 1997, p. 36). The unitary-transformative paradigm permits nurses to attend to the pattern of unfolding of a person’s life.

Nursing intervention is a form of nonintervention; the presence of nursing assists these individual to recognize their own patterns of interacting with the environment without judgment, goals or strategies (Newman, 2003). The nurse-client relationship is characterized as “a rhythmic coming together and moving apart as clients encounter disruption of the organized, predictable state and moving through disorganization and unpredictability to a higher, organized one” (Newman, 1999, p. 112). In letting go of

prediction and control, the nurse is able to concentrate on what is most meaningful to clients. There are many advantages to using this theory with the informal caregiver population in both nursing practice and research. With pattern recognition comes “the potential for action and within that potential comes the possibility of transformation” (Newman, 2003, p. 245). Movement through the period of disruption, disorganization and uncertainty is facilitated by the presence of a caring other.

Health as Expanding Consciousness and Family Caregiving

Despite the unspoken need to understand the story of an experience and what the experience means in the context of each life story, most individuals rarely take the time to consider what is meaningful to them. Nursing presence in an ambiguous, uncertain time may assist family caregivers to get in touch with the meaning of this experience and come to a new insight into the pattern of the process and the potential for action and transformation. The dynamic, holistic nature of this experience is consistent with the unitary-transformative paradigm (Newman, 1997).

The thing that brings people to the attention of a nurse is situation that they do not know how to handle. They are at a choice point. Each of us at some time in our lives is brought to a point when the old rules do not work anymore, when what we have considered progress does not work anymore. We have done everything right but things still do not work... This means learning how to transcend a situation that seems impossible, to find a new way of relating to things, and to discover the freedom that comes with transcending the old limitation. The necessity of “hanging in there” in the midst of the uncertainty and ambiguity of the chaotic situation is an important factor in the healing process....We as nurses enter into the process with a client to be present with it, attend to it and live it, even if it appears in the form of disharmony, catastrophe or disease (Newman, 1999, p.99).

There are many advantages to using the unitary-transformative paradigm in the caregiving population. The nurse enters into a partnership with a client when the client is

experiencing disruption and possible uncertainty. Based on existing literature and clinical experience, this disruption and uncertainty are undeniably present for those individuals who assume the caregiver role of a loved one after cardiac surgery. In addition to barely acknowledging their own changing needs and demand, the caregiver has to assume the care of the postoperative patient who is evolving through his or her own drastic life changes. With decreased length of postoperative stay in the hospital and an increased acuity at the time of discharge, the informal caregiver is bombarded by responsibility, concern and fear. Confounding this chaos is the negative connotations associated the burden, anxiety, uncertainty and stress that are affiliated with caregiving. Furthermore, nurses often place the emphasis on the care recipient or in this case, the postoperative patient. Consideration needs to be given to these caregivers both as individuals and as part of the caregiving dyad.

The nurse, who comes to this situation with the unitary-transformative perspective, dialogues with these individuals to discuss importance and meaning of this caregiving experience. Through an authentic, mutual relationship the nurse and client begin the process of mutuality and authentic presence which allows for the opportunity for the interpenetration of the client's and the nurse's pattern that includes the client's concept of health and the nurse's theoretical understanding (Newman, 2002b). The client guides the discussion, not the nurse. Clarity reveals itself as the nurse reiterates to the client what is heard and determines what is important. The authentic presence of a caring other may facilitate clients' health experience (Newman, 2002a). By viewing the client as a unique unitary whole, integral with his environment, nurses empower clients by

discussing choices and potential opportunities in how they react to their predicament, and by focusing on their strengths.

The unitary approach centers on meaning and requires a method of inquiry that is interactive and receptive to the pattern of the whole. The hermeneutic dialectic method allows the pattern of person-environment to reveal itself without disturbing the unity of the pattern (Newman, 1999). It seeks to capture the evolving, transformative nature of the nurse-client relationship. There is an a priori nature in this theory in that the researcher embodies the theory of expanding consciousness. Nurses frequently encounter clients in moments of disruption and chaos. To a nurse it is a privilege to bear witness to these individuals' transformation and evolution to a higher level of organization.

In summary, there are many advantages to using this theory with the informal caregiver population in both nursing practice and research. By using the unitary-transformative perspective, nursing will be able to develop a fuller understanding of what the caregiver experiences, and what these individuals bring to this experience. Based on this, nursing will be able to develop improved methods to understand this experience and better capture the informal caregiver's ability to deal with the ensuing chaos and uncertainty found in the assumption of this role.

Margaret Newman has stated how a person is viewed determines care (Newman, 1999). By using the unitary-transformative paradigm, we view the caregiver as an essential and integral partner in the health experience. By allowing the unfolding of pattern and the transformation that subsequently occurs, both the nurse and the caregiver

gain access to a higher level of consciousness. It is within this mutuality that both nurse and client will develop knowledge.

Research as Praxis, Health as Expanding Consciousness and Caregiving

There is research that utilizes Newman's Health as Expanding Consciousness and its research methodology including studies that focused on life meaning and cancer (Barron, 2000); women maintaining weight loss (Berry, 2004); Japanese women with ovarian cancer (Endo, 1998); expanding consciousness in midlife women (Picard, 2000); women living with rheumatoid arthritis (Neill, 2002); living with chronic skin wounds (Rosa, 2006); and older adults living with chronic illness (Noveletsky-Rosenthal, 1996). This research provides evidence that supports the importance of a nurse's supportive partnership with the client in allowing the process of expanding consciousness to unfold. The review of the literature produced two studies that utilized Newman's research methodology with family caregivers. One study involved twelve family caregivers of individuals affected with schizophrenia (Yamashita, 1999). The second study, conducted by Endo (2000) involved ten wives-mothers hospitalized with cancer and their primary family caregivers.

Phenomenological research has found a place in the study of caregivers of individuals with Alzheimer's disease (Loos & Bowd, 1997); parental liver donation (Forsberg, Nilsson, Krantz, & Olausson, 2004); impact of children with chronic illness on fathers (Goble, 2004); the experience of long term ventilator assistance on the patient and family (Ingadottir & Jonsdottir, 2006); bereavement and the family (Kissane, McKenzie, & Bloch, 1997); and HIV/AIDS (Lamendola & Newman, 1994). However, no studies to

date have focused on the overarching framework of universality of pattern across individuals as spousal caregivers of individuals recovering from coronary artery bypass surgery.

Chapter Summary

This chapter presented an overview of the literature relevant to family caregiving specifically within the cardiac surgery population; cardiac surgery including the changing patient demographics, hospitalization stay and the increased shift of care to the home setting; the recovery process from cardiac surgery in both the hospital and home setting; the effects of this surgical intervention in the setting of co-existing chronic illnesses; existing intervention studies focusing on the coronary artery bypass population; and Newman's Health Theory as Expanding Consciousness is further elaborated on along with a review of research studies that support the use of Health as Expanding Consciousness as a framework to guide research. Research to date concerning spousal caregivers of the cardiac surgery patient recovering at home has focused primarily on the caregiver's perception of the spouse's recovery and issues around discharge planning, knowledge deficits and task performance.

The review of the literature demonstrates a need for further investigation into the caregiving experience in relation to caregivers' life pattern and personal meaning. Gaining insight into this experience through the perspective of Newman's Health as Expanding Consciousness may yield an increase in nursing's understanding of caregivers and promote intervention strategies that will impact the caregiving experience.

CHAPTER THREE

METHODS

The purpose of this dissertation was to gain an understanding of the meaning of the lived experience for spousal caregivers of the postoperative coronary artery bypass surgery patient. An improved understanding of the perspective of these caregivers over their lifetime and how this informs the caregiving experience will enable nursing to identify the issues and needs of this population and more fully assist these spousal caregivers during this stressful, overwhelming period. For the purpose of this study, two questions were posed: 1) What is the life pattern manifested by an individual caring for spouses who have had CABG surgery? 2) What were the thematic expressions of life patterns among individuals caring for spouses who have had CABG surgery that emerged from this investigation?

This chapter includes descriptions of phenomenology, hermeneutics, the hermeneutic dialectic method, and Newman's Health as Expanding Consciousness research method. The study design including the pilot study, setting, sample, protection of participants' rights, data collection and analysis, rigor and validity are also discussed.

Design

The theoretical framework used to guide this study was Margaret Newman's Health as Expanding Consciousness (Newman, 1999). Central to this theory is the hermeneutic dialectic method which emerged from hermeneutics (Cohen, Kahn, & Steeves, 2000). Newman's research methodology permitted the identification of patterns

and the recognition of expansion of consciousness in the individual (Newman, 1999; 2008).

Phenomenology

“Phenomenological understanding is distinctly existential, emotive, enactive, embodied, situational, and nontheoretic; a powerful phenomenological text thrives on a certain irrevocable tension between what is unique and what is shared, between particular and transcendent meaning, and between the reflective and the prereflective spheres of the lifeworld” (van Manen, 1997, p.345).

Phenomenology can be defined as a philosophy, an approach and a research method. It is often considered an appropriate choice when an investigator is researching a phenomenon about which little is known (Munhall, 2001). The researcher who uses phenomenology focuses on interpreting the meaning within a phenomenon that is not immediately apparent to direct investigation, analysis and description (Omery, 1983). The phenomenological approach allows an investigator to craft an understanding of an experience through interpretation and then present that interpretation so that others may also comprehend the meaning in an individual’s experience (Munhall, 2001). A good phenomenological text has the effect of making us suddenly ‘see’ something in a manner that enriches our understanding of everyday life experience (van Manen, 1997). Therefore, the focus of phenomenology is human involvement in the world, the lived experience of individuals (Merleau-Ponty, 1962).

Heidegger, an interpretive phenomenologist, discussed how humans are embedded in their world to such an extent that subjective experiences are inextricably

linked with social, cultural, and political contexts. Interpretation of these human experiences leads to an understanding of meaning for these individuals (Lopez & Willis, 2004). Central tenets to Heidegger's phenomenology are the concepts of Lifeworld, individuals' realities that are invariably influenced by the world in which they live; and Being-in-the-world, the idea that humans cannot abstract themselves from the world (Heidegger, 1962).

The life world is the world lived in by an individual and is a world that is filled with experiences and relations. It is within this life world that an individual has lived experience. Human beings experience life and meaning through their bodies, their relations with others and through interaction with the environment. The lifeworld themes or existentials, articulated by Merleau-Ponty (1962), include spatiality, corporeality, temporality and relationality. These four fundamental existential themes are present in the lifeworlds of all human beings and serve as guides for reflection in the research process. They may be differentiated but cannot be separated; they form "an intricate unity which we call a lifeworld" (van Manen, 1990, p. 105). Although each theme or existential may be examined separately during the research process, it is essential to recognize that they exist only through an interrelational process with the each other. The examination of all four existentials provides a process for reflection, analysis and subsequently produces a richness of meaning that lies within an experience (van Manen, 1990).

Hermeneutics and the Hermeneutic Dialectic Method

Hermeneutics

Inherent to hermeneutics is the perspective that individuals present to a situation in the light of their own pre-understanding of their a priori worlds. The acknowledgement of self is necessary for this participatory perspective; one cannot be a detached observer (Gadamer, 1976). Hermeneutics originated as a philosophy concerned with human understanding and the written text. The word, derived from the Greek word *herausis*, means power of invention or discovery and was associated with Hermes, the Greek God of communication and human understanding (Dowling, 2004). The term hermeneutics originated in the 17th century when it was used as a way to interpret biblical and classical literature. Daniel Ernst Schleiermacher was deeply involved in the founding of modern hermeneutics in the 18th century. In the 19th century Wilhelm Dilthey developed methodological hermeneutics which called for placing a text within the social and cultural context of its production (Pascoe, 1996).

Hans-George Gadamer, in his work “Truth and Method”, built on the evolution of hermeneutics further by stating that philosophical hermeneutics is an ontological rather than methodological undertaking. (Gadamer, 1976). This thinking was often criticized for lack of method or methodology in his philosophy but Gadamer emphasized the need for a methodical direction and a systematic approach during interpretation. He believed that hermeneutics explains the circumstances under which understanding takes place, not the understanding itself (Walsh, 1996).

Gadamer's concepts included the notion of prejudgment or prejudice. This concept is not viewed as the modern definition with which we are familiar. Prejudice or prejudgment within this context explains the historical reality of one's being and is the basis for one's ability to understand; it is the theoretical and conceptual assumptions that one brings to one's observations (Pascoe, 1996). Gadamer believed that true understanding comes from a reciprocal process of interpretation that occurs through dialogue; his philosophical hermeneutics has a strong emphasis on language. Understanding is always obtained in the context of language and tradition. He is associated with critical hermeneutics, which claims that social, political and economic forces inhibit and bias interpretation. Gadamer emphasized the importance of recognizing these forces and their implications and of exposing individuals to these meanings that they may not recognize (Dowling, 2004). Hermeneutics is essentially the love of wisdom and a search for the best way to understand human existence.

For Gadamer, understanding was viewed as both a process and a mode of being (Gadamer, 1976). An individual used understanding to assess the way problems were engaged with the present. Being (existence) was viewed as foundational for hermeneutics. When human beings are seen as the center of a world that stretches out in all directions at all times; they are integral part of this world. An individual's experiences are interwoven in this world and produce Being. We attempt to understand this Being through these contingencies of space, time and culture (Steeves & Kahn, 1995). These contingencies are viewed as pre-existing understandings that influence our interpretations of the world and are acquired through language and produce traditions.

The principle of “horizons” is also considered essential to understanding the world. Horizons are quantified as limited (overvaluing the familiar), but are neither fixed nor static. They are the range of vision from a particular stand point (Wiklund, Lindholm & Lindstrom, 2002). Gadamer discussed the idea of fusion or merging of horizons in detail (Gadamer, 1976). This idea was regarded as a process that occurred through observation and study. Within this process, one came to understand one’s own horizon and then was able to incorporate the meanings of another individual’s horizon into his or her own. This produced a greater understanding of self, moral awareness, and appreciation of other vantage points (Lopez & Willis, 2004). Gadamer also emphasized the need for a reciprocal process and personal involvement of both parties in order to have a true interpretation and understanding of the meaning of a phenomenon of interest (Priest, 2004).

Hermeneutic dialectic

The dialectic process, the art of investigation of truth through discussion, is also essential to hermeneutics inquiry. This inquiry can be viewed as a pendulum that swings between part and whole. The continual shift between the part and whole produces a hermeneutic circle: a dynamic, equal, democratic process that produces an expansion of horizons. An individual examines the whole through the parts that are specifically based on the initial understanding of the whole. This subsequent new understanding provided by these parts produces a new whole. The cycle begins again as new parts are delineated from the new whole (Steeves & Kahn, 1995). The goal is to use the hermeneutic dialectic process to create a simultaneous view at all levels of inquiry.

For those who are critical regarding objectivity in hermeneutics, it is important to note that for Gadamer objectivity was seen as highly subjective. Gadamer (1976) rejected the notion of object-subject. His concept of the hermeneutic circle portrayed individuals interacting, as players who moved to and fro in an effort to lose subject-object distinction and who truly come to know each other through a genuine desire to understand. His emphasis was that understanding is an historical act always connected to the present. Interpretations could not be made as a subject relating to an object because there was an attachment between the two individuals that negated this mode of the detached observer. This connection allowed for true understanding in the context of language, cultural traditions and of what was significant to those involved. The best way that objectivity can be represented in hermeneutics is by being faithful in the representation of the research content. Accurate transcription of contents is in of itself not ideal as those who read research findings do so from within their own horizons (Fleming et al., 2003).

Dialogue, questioning and conversation were central to Gadamer's philosophic hermeneutics (Truglio-Londrigan, 2002). It was through conversation that one collected data as one immersed oneself into the subject matter and came to understand the shared meanings and common themes. Priest (2004) wrote that understanding and interpretation were reciprocal processes in hermeneutics. This practice depended on the personal involvement of the researcher and participant because in hermeneutics, interpretation permeated every stage of the research process. The researcher becomes the research

instrument that allows comprehension and understanding of the research matter (Fleming et al., 2003).

Observing the participant and establishing a collaborative relationship is crucial for the hermeneutic dialectic process to be successful for the researcher (Cohen et al., 2000; Gadamer, 1976) and includes:

1. Reflecting on the essential themes which characterize the phenomenon
2. Describing the phenomenon through the art of writing and rewriting
3. Maintaining a strong and oriented pedagogical relation to the phenomenon
4. Balancing the research context by considering parts and whole.

By adhering to these activities, the researcher may achieve Van Manen's definition of phenomenological research: the study of lived experience; the description of the experiential meanings as we live them; the human scientific study of phenomena and the search for what it means to be human (Oiler Boyd, 2001).

Newman's Research Methodology

Newman's Health as Expanding Consciousness is a hermeneutic dialectic method with its roots in phenomenology. Newman's methodology is known as research as praxis. Research as praxis is defined as "thoughtful reflection and action that occur in synchrony, in the direction of transforming the world" (Newman, 1999, p. 92). This combination of reflection and action permits the researcher to be an integral and interactive part of the experience. The researcher embodies theory, the participant is

experience; these two elements become entwined as the individuals interact. The researcher enters into a relationship with the participant at a time of disruption or uncertainty in the participant's life. The creative presence of the researcher enables the participant to have insight into his or her experience (Newman, 1999).

There are specific elements of the research process as outlined by Newman (Newman, 1999). First, there is the need to establish the mutuality of the process of inquiry. This occurs in the setting of an intentional relationship between the researcher and the participant. The nurse researcher is authentic and present in the moment and the participant is open to the experience. The process begins whenever the participant wishes to start. The participant is invited to "Tell me about the most meaningful experiences and people in your life starting with your childhood". The dialogue begins with the participant's unfolding of a story in a mutual process with the nurse researcher fully present to the participant. The nurse researcher listens to the unfolding story and guides the participant through a reflective experience if needed. The participant's reflections are then organized as a narrative with chronological ordering of the individual's meaningful events and people from childhood to present. The narrative is then displayed in a diagram reflecting pattern over time. The narrative and diagram as well as the researcher's perception of the pattern of relationships are shared with the participant in a second interview. The participant is given the opportunity to validate, clarify or expand upon the story or events until there is consensus. The researcher then identifies evidence of pattern recognition and insight into the meaning of the client's life pattern with the application of the theory of Health as Expanding Consciousness.

Pilot Study

The pilot investigation was designed to experience Newman's research as praxis with spousal caregivers of patients following CABG surgery. The pilot work consisted of two participants who had spouses recovering from coronary bypass surgery. Newman's research methodology was used as a methodological approach to understand the experience of these spousal caregivers in the month following discharge from the hospital. Each participant was recruited for the study prior to surgery at the preadmission testing appointment and consented prior to discharge from the hospital. Internal Review Board approval was obtained from the participating hospital.

Sample

The sample included spouses of individuals recovering from CABG surgery. Participants met the following criteria. Inclusion criteria for the spousal caregiver were as follows:

- Was an individual who resides in the same home as the postoperative patient.
- Was either the husband or wife of the postoperative patient.
- Would provide primary care for the postoperative patient during the first month of post-hospitalization recovery.
- Was able to read and write English.
- Was able and willing to participate in study.

Exclusion criteria included:

- Spouses of emergent coronary artery bypass surgery patients
- Spouses of postoperative coronary artery bypass surgery patients requiring readmission during the first month after discharge to home

A total of four participants were recruited and consented to participate. One of the participants withdrew from the study approximately one week after discharge from the hospital due to feelings of being “too overwhelmed to be in a study”. The second participant required readmission to the hospital and therefore failed to meet inclusion criteria. The remaining two participants and spouses met inclusion criteria and arrangements were made to meet for the interview process.

Setting

The interview was conducted in the home of one participant and in a private conference room at the participating hospital for the second participant. The conference room was in a separate geographic location away from the Cardiac Surgery Unit and provided private access for the participants. Both of the interviews occurred at one month post discharge and were audiotaped with participants’ permission.

Procedure

A mutually agreed upon date, approximately one month after discharge from the hospital was established with the spousal caregiver prior to discharge from the hospital. This date was negotiated based on the caregiving role demands and the postoperative care needs of the recipient that occurs in the first month after CABG surgery. Two weeks after discharge, the nurse researcher contacted the participant to confirm participation and ability to meet at the schedule time. Prior to discharge from the hospital, each spousal caregiver was asked to keep a caregiver journal. Caregivers were instructed to write in either full narrative format or randomly write down meaningful issues, thoughts, reflections and/or emotions that occurred at any time during the one-month time frame

between discharge from the hospital and the first interview. In addition, a demographic information sheet was given to the participants to obtain age, gender, ethnicity, educational level, length of stay in the hospital and socioeconomic status.

Prior to the interview, the nurse researcher spent five to ten minutes alone to center herself and prepare for an intentional interaction with the participant. The dialogue opened with an invitation: “Could you tell me about the most meaningful people and experiences in your life and your life as a caregiver in this experience?” (Newman, 1999). Branching questions were used to clarify the participants’ responses in dialogue. Following the interview, the tapes were transcribed within 48-72 hours by the researcher. A narrative was developed and the meaningful events and individuals cited by the participant were organized in developmental phases of the participant’s life and depicted in a visual representation. The relationship between the participant and these meaningful events and people were described under each phase depicted. A visual representation of relationships was then diagrammed. The participant was designated in the center of the diagram with the following symbols used to represent relationships:

1. solid line with arrows at both ends: an established, strong, continuous, meaningful relationship
2. solid line with an arrow at one end: a one-way connection that indicated a nonreciprocal relationship
3. broken line: a disrupted relationship that no longer provided meaning and/or support

Key phrases from the narrative accompanied the diagrammatic depiction of the participant’s life. Together these data were studied and a pattern analysis manifestation was displayed reflecting the participant’s life pattern. A wavy line at the bottom of the diagram was used to represent the flow of the participant’s life in relation to the

meaningful events and people in his or her life as discussed. Following this, the participant's pattern analysis was placed within Young's Stages of Evolution to assess where the individual was in the evolution of higher consciousness.

One week following the initial interview, a second interview was scheduled to review the narrative analysis. This gave each participant an opportunity to reflect on the pattern display for accuracy and to clarify or modify any information that he or she deemed meaningful. The narrative summary and the pattern analysis were shared with the participant. The participant was given time to make his or her own interpretation of the experience after examining the data and pattern construal and to validate the nurse researcher's portrayal of the participant's story. A third opportunity to meet was then offered to the participant in an effort to support further reflection, insight and meaning and make changes to the narrative as needed.

Participant One: Olga's Narrative Summary

Olga chose her home as the setting for the first interview. She was quite adamant about having her spouse present during the encounter. The interview began with an explanation of the study and the query "Could you tell me about the most meaningful people and experiences in your life and your life as a caregiver in this experience?" The interview process proceeded according to the methodology proposed and lasted approximately 90 minutes. The participant shared how her relationship with her husband was most important and how they have always taken care of each other. He had cared for her during her own health crises

We like the same food, we like to do the same things, we like everything (laughs). So, um. You know, he took care of me four times. I had to have part of my

thyroid taken out and then I had a brain aneurysm on my left side in 1985. I was sick for a year and a half. I walked like this (left foot turned in and dragging it as she walks) and um.... I came right home. I was pretty out of it for a year. Not really out of it, but I couldn't do anything.

When reflecting upon her spouse's recent heart surgery and recovery, she discussed how they very much depended on each other to work through the health crisis and recovery.

I just wanted to take care of him, period. Our son flew in from XXX and stayed to help us out that first week. He went to the doctor's with us and helped make appointments. But you know, he is busy too and he had to get back. He calls every day to see how things are going. I would never tell him about all the work that needs to be done around here. He would hire someone but we would rather do it ourselves. This is our home and our work.

Following the interview and subsequent transcription, a narrative was developed. A pattern analysis was completed and significant relationships were organized within the developmental phases with pertinent comments from the narrative placed within phase. Significant relationships were diagrammed using the established key. A wavy line representing the flow of pattern across the life span was created. A smooth wave was used to represent flowing, nonchaotic periods. Large, frenetic loops were used to represent periods of chaos and turbulence (See Appendix C, Figure 2). The pattern analysis was then assessed for expansion of consciousness. This was done by using Young's Stages of Evolution.

During the second interview, the narrative summary and diagram were shared with the participant. She remarked upon how precise the portrayal reflected her life story as an individual and as a spouse. She also acknowledged how with each challenge in their

lives, she and her spouse had turned to each other to such an extent that the dependence they had on each other at times did not allow other people the chance to assist them.

That's true, that's true. You know, my son wants to come back out to help but I told him no. And, the fire department keeps wanting to come help but Bob doesn't want anyone other than me to help him.

When pointed out the many times she spoke about fatigue and how she fell asleep behind the wheel of the car while driving her spouse home from the hospital for a follow up appointment, she was quiet. After a few moments she said:

That really scared me. I could have really hurt Bob. But I guess I could have really hurt myself, too. You know, I just don't even think about asking for help. I know people would be happy to help; I just don't want to have to ask them.

The participant reflected on how during every significant event in her life, she had allowed only her husband to be involved: the birth of their only child, both of their multiple illnesses, building their home together. She and her spouse made themselves available to others in need but refused help when offered to them. While looking at the diagram, she remarked how she was not close to her parents, but now that her mother was ill (terminal cancer), she was close to her:

We did everything for them and with them, everything there ever was, yes everything. I am not close to them especially since....well I am close to my mother now especially since she is so sick.

I have one sister and I am not close to her (said very emphatically). She was married and he left her and she married this other guy and really you don't want to know about it. He was an alcoholic and abused her twin boys something fierce. I don't need to tell you what he did to the daughter, but my sister was right there and she knew what was going on. And we tried to help and she didn't do a thing and you know, we just don't live like that. So we just don't associate with them at all.

The participant was silent for several seconds and then said:

Maybe it's time that I let someone help us. I could have killed Bob and me that day. Especially after all that we have just been through. I'm no spring chicken. Maybe I could at least get someone to help with the yard work so I can focus on Bob.

This reflection within the setting of a strong mutual interaction between the participant and the researcher permitted this new insight and meaning to emerge. The theme "Allowing Others In" began to emerge as a whole based on Olga's reflections. In Young's spectrum, Olga was at the stage of Choice; she was beginning to acknowledge the need for help from others and was starting to reach out.

Participant Two: Jim's Narrative Summary

The second participant chose the private conference room at the hospital for both interviews. Jim had returned to work and it was more convenient for him to stop at the hospital on the way home. This room was well lit, with a table surrounded by chairs in the center of the room. The nurse researcher met the participant outside of the room. Jim was given some time alone to "gather his thoughts" while the nurse researcher took the opportunity to focus and center in preparation for the interview. The first interview lasted 60 minutes and proceeded as described with the previous participant.

"Jim" was initially concerned that he had nothing to contribute to the study. He felt like his wife, the recovering open heart surgery patient, would be a better source. The purpose of the study was described to him and his role in the study was defined. He agreed to continue.

When we met for the second interview, he was curious about what he would find. When the pattern construal and narrative were shared with him, he found it “fascinating”. (See Appendix C, Figure 3).

Yeah, I guess that is me. Lot of work on one piece of paper. You’re right, if I didn’t have my wife telling me how to take of her, I think I would have been a bit lost. But, that is the way it has always been (laughs). She raised the kids and ran the house.

The only thing I did was look up some stuff on the computer. But that helped me and her. I figure, I just do what she wants me too and I don’t ruffle her feathers. That is the best way for me to be and that has always worked for us. Since way back in high school!!

Jim was encouraged to share further reflections regarding the pattern appraisal but he stated he really had nothing to add at the time. A request to meet for a third meeting was politely declined as he felt that he had nothing further to contribute. Jim was asked if he felt had learned anything from reviewing the pattern appraisal. He stated “what my wife and I have works in good times or bad.” Jim was placed at Binding on Young’s Spectrum. The pattern that emerged for Jim was “Allowing Others to Control”.

Discussion

These pilot study interviews supported that the proposed research questions could be answered using Newman’s Research as Praxis. Each case allowed for the meaningful experiences in the participants’ lives to evolve. New understanding regarding this caregiving experience was uncovered. By using phenomenological analysis, the researcher was able to identify emerging trends but recognized the need to re-evaluate this information in view of a larger data set using the research methodology proposed.

Lessons Learned

Pilot Findings. Both of the participants agreed that scheduling the first interview one month after discharge was too long from the discharge from the hospital. They stated that with the resumption of normal activity by both the recovering spouses, it was difficult to regain the emotions that they were feeling during the earlier phase of home recovery. Both had been requested to keep a caregiver journal but neither one did. They both stated that this was due to the fact that they felt overwhelmed by paperwork from the hospital, insurance companies and other healthcare providers including primary care physicians, cardiologists and cardiac rehabilitation.

Although offered the opportunity to have a third meeting to discuss their reactions to the reflections and findings of the second meeting, both declined. Both participants felt that they were ready to resume the preoperative “normal routine” and wanted to minimize further interviews and appointments.

Proposed changes. Based on the pilot data, the contact interview was changed from one month to two weeks after discharge. The two week post discharge period was selected in order to allow the spouse and the recovering patient the time needed to move through the critical first week after discharge to home. Rescheduling the first interview to this earlier timeframe enabled the participants to have potentially more accurate recall of the caregiving experience and permitted the nurse researcher to capture the complexity of the caregiving experience as it unfolded. The participants were encouraged to keep a caregiver journal in order to maximize recollection of the experience. Innovative ways to assist with recollection such as audiotaping, photography and drawing were added to the

experience to help the participants communicate their experience. Although neither participant chose to schedule a third interview, this opportunity was continued for those individuals who desired further opportunities for discussion and reflection. At the minimum, a telephone interview was planned one week after the second interview to give the participants an opportunity to communicate reflections and concerns. There were no added changes to the method. The researcher recognized that upon dwelling with the data, there were times when extended responses were needed or the researcher needed to be in the moment and the data would flow. In an effort to insure that the researcher was using the method as designed and capturing full response of the participant, subsequent interviews, narrative summaries and pattern analysis were reviewed by the dissertation committee members who were experts in phenomenology and Newman's Research as Praxis.

The Proposed Research Study

Sample

The sample population was obtained through purposive sampling technique, as the phenomenon studied was specific to spouses of recovering cardiac surgery patients.

The following inclusion criteria were used in the study:

- The spousal caregiver was an individual who resides in the same home as the postoperative patient.
- The spousal caregiver was either the husband or wife of the postoperative patient.
- The spousal caregiver provided primary care for the postoperative patient during the first month of post-hospitalization recovery.
- The spousal caregiver who assumed primary care of the postoperative patient was able to read and write English.
- The care recipient was a postoperative elective cardiac surgery patient.

- The caregiver was able and willing to participate in study.

The following exclusion criteria were used in the study:

- Emergent cardiac surgery patients
- Patients requiring readmission

The determination of the sample size was dependent on the researcher's judgment and experience in assessing the quality of the collected data; other key factors included the research method used, the sampling strategy and the intended research product (Sandelowski, 1995). Estimating this study sample was influenced by the need for identification of patterns unique to each individual and then the recognition of themes across participants. Newman stated each nurse/participant relationship is unique and is formed by the informational patterns of the nurse and participant. Pattern conveys the connection of a meaningful whole that guides the potential for discovery, choice and action possibilities (Newman, 2008). Within Newman's research methodology, the nurse researcher seeks to identify similarities and variations of patterns among individuals with similar life circumstances while at the same time honoring the uniqueness of each individual and each nurse/participant relationship (Newman, 1997; 2008).

Setting

The setting for this study was either in the spousal caregivers' homes or at the hospital in a private conference that has been delegated for study participants. Each participant was encouraged to choose the location that was comfortable and allow them to fully share their experiences. The first interviews lasted between 60-120 minutes and the second interview, again at the location of the participant's choice, lasted between 45 to 60 minutes. The option for a third interview remained available to the participants and

was scheduled within a week of the second interview if desired. If the participants choose not to meet for a third time, then a telephone interview took place within one week of the second interview.

Informed Consent/Protection of Rights

Approval for this study was obtained from the Boston College School of Nursing Human Participants Review Committee and the Boston College Human Participant Review Committee as well as the Internal Review Board (IRB) of the participating hospital. The consent explained the study, its goals, any potential risks and the right of the participants to withdraw at anytime. The consent addressed how confidentiality of the participant would be maintained along with any third parties named and discussed during the interview.

During the transcription phase, done by the nurse researcher, pseudonyms were used for the participants and third parties mentioned within both the interview session and caregiver journal in an effort to maintain anonymity and confidentiality. The participants chose a pseudonym or one was assigned. A master list of the identification numbers of the participants was kept in a secure place and accessed only by the researcher. Once the study was completed, the master list was destroyed in order to maintain patient confidentiality. The research project was performed under the guidelines of the National Institute of Health Office for Protection from Research Risks for the Protection of Human Rights. ([United States](#) Department of Health and Human Services, 2006).

If the participant became distressed during any phase of the interviews, the interview was discontinued and appropriate resources put in place to support them were accessed with the participant's permission. Member of the Pastoral Care department at the participating hospital agreed to act as a resource for the participants in this study. If at any time during the research study the participant requested not to continue, he or she were allowed to do so. Participants were informed that termination of participation in the research study would not compromise the continued care of their spouse by Cardiac Surgery team at the hospital.

Data Collection

Procedure

Study design included two or three face-to-face interviews based on Newman's research protocol. The first interview took place two weeks after discharge from the hospital to home. The selection of this time was based on findings from the pilot study. Each interview was audiotaped and spousal caregivers were encouraged to keep a journal. The journal had a two-fold purpose: the contents served as a memory aid when the participant was being interviewed and also had the potential to serve as a therapeutic device for the caregiving individuals.

Prior to the each meeting, the researcher took time to become centered using brief meditation. A minimum of two interviews took place for each study participant. The interviews were based on Newman's (1994) research protocol. The first interview was semi-structured and in addition to the first request, "Tell me about the most meaningful people and experiences in your life", questions were asked to clarify information or to

redirect the participant to the specific question. The nurse researcher took notes during the interview processes that were used later during data analysis.

One week following the initial interview, the researcher met with the participant at the location of his or her choice to review the narrative analysis and pattern construal. This allowed the participant an opportunity to reflect on the research findings with the nurse researcher and clarify or modify any information that he or she deemed meaningful. Pattern recognition was appraised through verbalization of an understanding of the life pattern and its influences on the participant's life and life choices. The second interview also gave the participants an opportunity to discuss whether or not participating in the study has had any influence, impact or meaning for them. Based on the each participant's experience, the option of a third interview was presented for further reflection and clarification. If the participant did not want to meet for a third interview, a telephone interview was conducted one week after the second interview. The participant was asked "What has been your experience since the last time I spoke with you?" This permitted the participant to articulate upon further reflection on the pattern recognition that may have occurred since the prior meeting.

Recruitment

Study participants were recruited for the study at the preoperative admissions visit with the Cardiac Surgery Nurse Practitioner. At that time a flyer was given to potential participants describing the study's purpose, design and data-collection methods. The potential participant was informed that, he or she would be approached on the first or second postoperative day by the nurse researcher to discuss the study in depth, the participant's

involvement and the projected time commitment. Inclusion and exclusion criteria were discussed and privacy issues were addressed. A period of at least 48 hours followed before obtaining consent for participation. Potential participants were reassured that the decision not to participate would have no effect on their spouse's care or on their own interactions with or treatment by the healthcare team.

Data Analysis

The data for each of the participants included the two interviews and the subsequent narratives and pattern construals. Data analysis was conducted in two phases. The first phase was the examination of the individual participant data generated by the Newman research method (2007). The second phase was the analysis of the data across participants for similar or different themes among spousal caregivers of postoperative CABG patients recovering at home.

Phase One: What Was The Life Pattern Manifested By Individuals Caring For Spouses Who Have Had CABG Surgery?

The same procedure was followed for each of the individual participants.

1. The researcher began analysis with a short period of meditation and centering.

The interviews were transcribed within 48-72 hours by the nurse researcher.

Repeated, in-depth readings of the transcriptions were conducted to allow for adequate reflection on the interview. This permitted the researcher to at first obtain an understanding of the participant's reflections as a whole. Significant reflections, phrases and statements were highlighted and then placed within the narrative.

2. The narratives were then arranged in chronological order described as childhood, young adulthood, adult, late adulthood and present. Meaningful events and people in the participant's life were placed within the appropriate time period and diagrammed using the established key.
3. Sequential patterns were identified and a diagrammatic construal was created. A wave-like line was used to represent the flow and the pattern of the individual's life. Meaningful events and disruption were represented by a shift in the pattern of the wave with an increasing spiral form representing an alteration in the flow.
4. Both the narrative and the pattern construal were shared with the individual at the second interview. This occurred within one week of the first interview. Comments regarding the meanings and reflections of participating in the study were incorporated into the narrative. Pattern recognition, if it occurred for the individual was discussed in detail. A subsequent interview, if desired, was scheduled at the request of the participant.
5. The data from the two interactions were reviewed in relation to Newman's theory of Health of Expanding Consciousness. The data also permitted the nurse researcher to place the individual on Young's Stages of Evolution from the Theory of Sequencing of Human Evolution. Placing the individual on this staging represented further determination of the participant's movement toward increasing freedom and higher consciousness.

Phase Two: What were the thematic expressions of life patterns among individuals caring for spouses who have had CABG surgery that emerged from this investigation?

Further analysis began with the comparison of patterns across participants. Analysis began with immersion in the data through multiple readings of all the individual narratives and pattern construals. With the emergence of similarities and variations of pattern among individuals there was the concerted effort to honor the uniqueness of each individual life pattern and nurse/participant relationship (Newman, 1997; 2008). The following procedure was used for analysis of data across participants.

1. The individual participant's narrative and pattern construals were reviewed allowing the researcher to focus on identifying patterns and descriptive expressions in the exact language of the participant.
2. The data were then reviewed for essential similar patterns across participants. Direct quotes and examples were taken from the data to corroborate the patterns. The data were examined once again to identify and confirm shared and common patterns across interviews relevant to spousal caregiving of the coronary artery bypass patient.
3. These common themes across participants were viewed within the context of Newman's Theory of Expanding Consciousness.

Rigor and Validity

"Rigor is being able to demonstrate an understanding of what and why the researcher did what he did – it is not about the application of a set of rules" (Rose & Webb, 1998). The end goal of research is a maximal understanding of a phenomenon that

holds clinical relevance for practice. It is essential that rigor and validity be established in order to disseminate research findings.

Guba's Model of Trustworthiness (Krefting, 1991) is a model that ensures rigor without sacrificing the relevance of qualitative research. In this model, Guba outlines four aspects of trustworthiness:

1. truth value which represents credibility;
2. applicability which refers to the fittingness of the data, rather than the generalizability;
3. consistency which is reflective of dependability;
4. neutrality which is applied to the data, not the researcher.

Guba delineates strategies to establish or increase trustworthiness in one's research through credibility, dependability, confirmability and credibility. This study used the following to establish credibility: The researcher was an integral part of the research, not separate from it; triangulation; member checking; peer examination; flexible interviewing process; and the unique authority of the researcher. The mutual partnership between the nurse researcher and the participants as well as the embodiment of the theory by the nurse researcher as set forth by Newman's methodology insured that the nurse researcher was integral to the experience. The unique authority of the researcher was fulfilled as this nurse researcher works as a nurse practitioner in cardiac surgery and deals directly with inpatient care, has a strong interest in conceptual or theoretical knowledge, the ability to take a multidisciplinary approach, and good investigative skills.

Dependability was demonstrated in this study by the exacting description of how the data was collected, analyzed and interpreted which will permit the study to be repeatable, auditable and amenable to peer review. Essential to the success of the study and demonstration of transferability was demonstrated by the representativeness of these caregiver individuals for spousal caregivers of cardiac surgery patients as detailed by demographic information. Confirmability was established through the ongoing auditing process of peer review. Peer review was accomplished through ongoing feedback and guidance from the dissertation committee in regards to the research process and findings. Member checks were an essential part of the study and allowed the participants to review and validate their transcribed data.

Validity was optimized in the following ways. The repeated interviews with the participants afforded them the opportunity to validate or modify the researcher's interpretation and diagrammatic representation of their pattern. This additional data were incorporated into the final individual interpretation. In addition, the findings of this study were compared and contrasted with the findings of other researchers. Furthermore, the findings of this study will be disseminated through publication and presentation with the hopes of promoting further discussion.

CHAPTER FOUR

FINDINGS

The purpose of this study was to gain an understanding of the meaning of the lived experience of spousal caregivers of patients following CABG surgery recovering at home. An enhanced understanding of the caregiver over his or her lifetime and how their life experiences informed caregiving enabled the nurse researcher to become aware of the changes needed to enhance recovery, assist spousal caregivers during a challenging life event and provide new opportunities for growth and development for the nurse and the care provider.

Results from this study are presented in three sections. Section one provides a brief overview of the study and sample demographics. Section two focuses on individual pattern analysis for the population sampled. Individual participant exemplars were presented along with the individual's narrative summaries and diagram of significant events, pattern analyses and the individual's reflections on their pattern construal as presented. Section three presents the researcher's insights to dwelling with the data across participants and presents themes that emerged in light of Newman's theory of Health as Expanding Consciousness.

Overview

This investigation posed two important questions: 1) What were the life patterns manifested by individuals caring for spouses who have had CABG surgery? 2) What were the thematic expressions of life patterns among individuals caring for spouses who have had CABG surgery that emerged from this investigation? The study and approach to

data analysis was grounded in Newman's Theory of Health as Expanding Consciousness research protocol as described in Chapter Three.

Sample

A total of 17 participants were recruited for the entire study including the two pilot study participants. One participant was excluded from the study when her spouse was readmitted for postoperative complications. Four participants withdrew prior to the first interview. One of these individuals stated that she was too overwhelmed by her caregiving responsibilities to participate in the study. Another participant stated he was no longer interested in participating. One participant's spouse, the recovering CABG patient, called and withdrew his wife from the study. A fourth participant felt that her spouse's recovery had been uneventful and thought she had nothing to contribute.

The final sample consisted of twelve participants between the ages of 45 to 75 years of age ($M = 65$ years; $SD = 9.95$). There were ten women and two men in this sample. The years married for these participants ranged from 18 to 53 years ($M = 39.4$ years; $SD = 12.9$). All of the study participants were Anglo-American. With the exception of one individual, all of the participants had completed high school. Two participants had partial college experience and four had completed a college degree. More than 75% of the sample had an annual income of \$41-60,000; one participant had an annual income of less than \$20,000; two participants' annual income was greater than \$100,000. One participant refused to disclose her financial information. The postoperative hospital stay for the participants' spouses was either four or five days overall.

Phase One: Individual Participant Exemplars

To answer the first research question, the nurse researcher followed the research protocol outlined by Newman (Newman, 1999). This involved a dialogue with each spousal caregiver followed by a second meeting to discuss the researcher's reflections on the data. Phase I of data analysis reveals the stories of each participant.

In this discussion to follow, two participants' stories are presented and include the narrative summary, the diagram, the participant's response to the pattern appraisal and the pattern analysis summary. The two participants were selected to represent the younger and older spousal caregivers in this study. For remaining participants, summary narratives are included in this chapter with the other data including the diagrammatic construals found Appendix D.

Exemplar One Sarah's Story: Protecting Self from Negative Experiences and Pain *Sarah's Narrative Summary*

When Sarah discussed her childhood she shared memories of being able to run to her grandmother when life was too stressful at home with her parents and sisters. Sarah's mother was diagnosed with breast cancer when Sarah was just four years old. Sarah's father, overwhelmed by his wife's diagnosis and the responsibility of caring for three young daughters, made the decision to send Sarah to live with her paternal grandmother. Her two younger sisters, ages two and three, were sent to live with her maternal grandmother.

Sarah recalled her childhood with her parents as being stressful with financial issues and her mother's health creating challenges. Her primary relationship was with her

grandmother. She did not recall being close to her parents or her sisters but considered herself the luckiest of the three sisters because of the warm, reciprocal relationship with her grandmother. That relationship started during the time she lived at her grandmother's home. Until her adolescence, Sarah spent most of her free time with her grandmother and viewed her grandmother's home as a haven from the stress that she felt existed between her parents.

Sarah met her husband when she was in her early twenties; he was in his mid thirties. Her husband had been married before and had a teenage daughter. They married after a few years of dating. Sarah remembers this period as a good time in her life. She established and maintained a strong, positive relationship with her stepdaughter. Despite the fact that Sarah's mother had several recurrences of breast cancer during this time, she did not recall her mother's illness as stressful for her. She has always felt that her mother survived the cancer during her first diagnosis and that she would survive again. She viewed the recurrences as positive because during this time she and her mother became closer.

When Sarah was in her mid twenties, she and her husband began their own family. She had a daughter and then later had twins, a girl and a boy. Sarah reflected how her children have been the most important part of her life; she found motherhood to be fulfilling. Sarah considered herself fortunate that she has been able to stay home with her children and participate in their school and extracurricular activities. She did not have that as a child and she is happy to be able to be there for her own children.

In her late twenties and early thirties, Sarah and her husband went through a series of changes in their lives. They lost their business due to financial difficulties. Her husband took a job working for a different company. Sarah recalls that losing their business was more difficult for her husband than for her. She had been minimally involved in the running of the business because of her focus on the children. Her husband on the other hand, was very disappointed and felt like he had failed his family by not succeeding in managing his own business. With a more stable income, Sarah and her husband were able to build a new home. Sarah stressed that this home was built with her grandmother in mind because Sarah had always planned to have her grandmother move in with her as she got older. As Sarah's grandmother became more functionally limited, she moved in with Sarah and her family. Sarah became the primary caregiver for her grandmother who suffered from COPD.

Also during this time Sarah's relationship with one of her younger sisters began to improve. Sarah shared that she had never been close with her younger sisters; she acknowledged that the three of them had very different views on life. She attributed this to the time they spent apart as young children when her mother was ill with cancer. Although Sarah and her sisters did return home after her mother began to recover from her treatments, Sarah believed that the time spent apart was very influential on their outlooks on life. The grandmother with whom Sarah stayed was loving and supportive while according to Sarah "there wasn't much love" in the maternal grandmother's home where her sisters stayed. She was optimistic however that her relationship with her sisters

could continue to improve and looked forward to closeness with them that she did not have as a child.

Just prior to her spouse's surgery, Sarah's father was diagnosed with prostate cancer. In discussing her father's illness, Sarah responded that she had decided she would help if asked but that she would not be overly involved. She expressed that she has felt calm about her family's health because everyone has always been "okay" despite frightening diagnoses. She stated she did not believe that her involvement in her father's care would help nor did she feel she had the time. She shared "I can't watch my husband, take care of my grandmother and the three kids and then worry about my father, too."

Sarah alluded to being aware of another significant emotion during this time before her husband became ill. Specifically, Sarah discussed that she realized that she made the right decision to have a life with her spouse. After a decade of marriage, Sarah realized how much her husband meant to her. She shared the following:

It wasn't until I was married about ten years that I started to realize that this was it, I had made the right choice. At 15 years into this marriage, I love him a lot and I know that there is no trading him. It would not make sense and I don't want to.

At the time of the interview, Sarah's husband was recovering from surgery, Sarah shared that she has never been worried about his recovery. She indicated that she was relieved that his disease was detected before he had a major heart attack. She believed herself to be lucky and recalled a time during the hospitalization that she looked around at the other spouses and realized how young she and her husband were in comparison. She felt that if something did happen to her husband she would feel less heartbreak than the older women because she assumed that she and her husband had less years together.

In the two weeks since her husband returned home from the hospital, Sarah felt like she did not have enough time to give to him. She was adamant that her husband take care of himself and that he is young enough and well enough to do so. At the same time, she felt like she was neglecting her grandmother and her needs. When asked about her children and how they reacted, she indicated that she did not allow them to visit her husband in the hospital and that they were doing fine since he has returned home.

Despite Sarah's denial of any worries when questioned, she spontaneously mentioned that when she and her husband sleep at night she listened to his heart beat and was afraid of not hearing it. When she talked about how she felt when her husband was in the hospital, she becomes tearful in the beginning of the conversation. She was quite taken aback by the fact she had been moved to tears in the context of the interview. She shared:

But I really, truly knew that he wasn't going to die and I really, truly knew that he was going to be okay. It wasn't easy and it took a lot of strength probably for me to stay there and not panic. And because I knew that he was going to be okay, I probably didn't need to cry about it.

I think I always stayed right at okay. I think I thought it would be silly to go crazy over it. What good would it do any of us? It wouldn't be good for the kids; it wouldn't be good for my grandmother, it wouldn't be good for him; it wouldn't be good for me. Until today, this made me cry.

Sarah's Response to the Pattern Analysis

Sarah's pattern analysis, based on both the narrative and the diagram did display an emerging pattern over time. Through the years, Sarah disconnected herself from the negativity she associated with stress and crises. When the pattern appraisal and diagram

that was interpreted was shared with Sarah at the second interview, she added further information:

I see what you mean about the wave (referring to diagram) here. You know, I have been very lucky because every time that something has gone wrong, everything has turned out okay. I don't look for what might go wrong because it never has. I don't like to let myself think about what that might be like. My sister says that I am like an ostrich putting its head in the sand (laughs). I like that sand. And you know what, I do know that I am lucky that I still have my grandmother but I know that won't be for much longer. So why not enjoy the time we have together. I think that about my husband now too. I am thinking that more than I probably would have if this (surgery) hadn't happened.

Sarah's Pattern Analysis Summary

Data were examined in light of Newman's theory and reflected on a thorough pattern analysis and development of Sarah's narrative and diagram. The pattern analysis revealed that Sarah's life pattern was one of protecting herself from negative experiences and pain. From early childhood on, Sarah perceived herself as being able to physically and emotionally remove herself from negative experiences. She used this behavior as a child to protect her from the painful experiences of childhood. Later she found an important person in her life, her grandmother, who gave meaning to her life.

Sarah had negative experiences in her life as well as in her immediate and extended families' lives that ended well. Her pattern revealed an ability to disconnect from negativity, first demonstrated when Sarah discussed her childhood time with her grandmother as her own mother battled cancer. She was sent away to live with her grandmother and came to view her as a haven from the stress that occurred in her parents' home. Sarah stated "I feel like she saved me in a lot a ways. When things were hard at home, I could run. It was like going to my own little piece of heaven."

CHILDHOOD	EARLY ADULTHOOD	ADULTHOOD	PRESENT
<p><i>“When things were hard at home, I could run.”</i></p> <ul style="list-style-type: none"> • M w/breast CA when S is 4 • S lives with grandmother; 2 sisters with other grandmother • Mother survives, S and sisters move home. F focused on M • very close to grandmother; “spoiled her rotten” • Parents w/stressful relationship • Not close to sisters • Spent less time w/GM as preteen 	<p><i>“My husband knew from the get go that I was going to take care of my GM.”</i></p> <ul style="list-style-type: none"> • Met husband when 23 yo. G is 12 yrs older. • Promised never to put GM in nursing home • S becomes closer to mother • Has 3 children: daughter then twin 5 years later 	<p><i>“I just take for granted that people live forever.”</i></p> <ul style="list-style-type: none"> • GM moves in. Never worried about family health issues • G’s brother dies of MI • Very religious, depends on faith • G & S’s business fails, G gets new job • Relationship improving w/one sister • Father diagnosed w/prostate CA • realized that she made the right choice w/G 	<p><i>“It makes me appreciate my life”</i></p> <ul style="list-style-type: none"> • Not worried b/c caught disease before G had MI • didn’t stay w/G in hospital • no time to care for him • Luckier than older wives • Felt like she neglected GM • Afraid of “not hearing his heart” • Cried for the first time during interview

Figure 2. Participant #11 Sarah (S): G: husband, GM: grandmother; M: mother; F: father; S1: sister, S2: sister; Fr: friends; Sd: stepdaughter; D1: daughter, D2: daughter; So: Son

In her adult years, Sarah protected herself by not acknowledging the possibility of a negative outcome. She stated: "I have had a lot stuff happen all ready in my life and it has always been okay. I guess I just take if for granted that people live forever." Her mother survived several recurrences of cancer; her father was currently battling prostate cancer and her husband recovering from surgery. While Sarah was dealing with these events, she was focusing on her grandmother and her children. Her grandmother remained a consistent figure in Sarah's life. This relationship appeared to enable Sarah to continue this pattern of self protection and disconnection from emotions. Sarah's grandmother lived with Sarah and her husband as they built their home with this objective in mind. Sarah continues to avoid emotional responses to negative experience as evident when she discussed her father's health issues and his prostate cancer. She indicated that she would help if she was asked to but otherwise is not involved because she is too busy taking care of her grandmother.

When Sarah discussed her husband's recent diagnosis and surgery, she shared that she was happy that this has occurred while he is young and able to recover easily. She admitted that she had not been active in his post-discharge care and referred to a lack of time as a primary barrier. She mentioned competing demands on her time such as time committed to her children and grandmother. When asked to discuss her responses to her husband's illness, Sarah cried and discussed her fears of "not hearing the (her husband's) heartbeat at night." This may be significant as being alone with her husband at night may be the only time that she allowed herself to become aware of the illness and the potential impact it is having on her.

Sarah's discussion about her husband's surgery and recovery as well as her expressed awareness of her grandmother's aging may be bringing Sarah to a choice point in her life where she realized that for the first time, all might not end up as well as can be expected. During the initial interview, Sarah discussed how she compared herself with the spouses of the other recovering heart patients. She appeared overwhelmed with trying to understand their potential heartbreak. "So I am sure that when it happens the heartbreak will only get worse the longer we are together. It makes me appreciate my life."

Sarah was at a choice point in her life where she was allowing herself to become aware of her response to the current and the past illness and connections in her life, both positive and negative. She was able to acknowledge that there was a possibility her husband not doing well and expressed an awareness of the emotional implications it would have for her and her family. She realized that her time with her grandmother may be limited and that for the first time in her life she acknowledged that she could lose two of the most significant relationships in her life. Sarah reached a point in her life where she has begun moving toward increased self-awareness, self recognition and a new understanding in regards to her life pattern of avoiding the emotional responses to with life crises. Using Young's Spectrum of Evolution, Sarah was placed at the stage of Decentering. As this new awareness continues, Sarah has the potential to expand her consciousness by accepting and acknowledging her emotions as she faces challenges in her life and creating new strategies to increase her ability to cope with potential problems

in her life. The theme “Protecting Self from the Potential Pain” emerged as the pattern expression of the whole.

Exemplar Two Mary’s Story: Fear of Uncertainty

Mary’s Narrative Summary.

Mary was the middle child who grew up in a stable, affluent home with her parents and two brothers. She had a close relationship with her family and reflected how her brothers always “took care of her.” Childhood was a happy time in Mary’s life and she recounted how she felt well-loved by her immediate and extended family as well as a close circle of friends. Mary recalled her one act of defiance as an adolescent when she refused to continue her education in boarding school. She stated how she “fought” to be treated like her brothers and be permitted to attend public high school. Her parents relented and Mary stated this was one of the happiest times in her life.

After high school, Mary’s brothers went to dental school and Mary continued her education to become a dental hygienist. She worked for her father in his dental office. As a young adult she encouraged her brothers to bring friends home from school. She felt like she was never going to meet anyone in her small town. Eventually, she met her husband. He, like her father and brothers, was a dentist and after they married Mary worked for her husband in his practice.

Mary seemed to be a woman before her time. She had four children and returned to work after each was born. Her last child was born prematurely and required hospitalization for an extended period of time. During the interview, Mary reflected that whenever she was pregnant, she always read the latest baby books but had never took the

time to read information other than what was “normal” for pregnancy and early childhood. When her last child was born prematurely, she scoured the literature for information on caring for a premature infant. She recalled this as a very stressful time as she attempted to manage three young children and a baby in the hospital. She shared:

I thought that they were going to send her into Boston but they did not. They let me bring milk in to her. Everyday I would come home, pump the bottles and cart the milk over there. They fed her with an eye dropper..2drops, 3 drops. Gradually she started to gain and once she got back to her birth weight they let me take her home. It was a lot easier once she came home. I didn't have to go back and forth to the hospital. You know when you've got kids you just figure it out and do it!

During the interview, Mary was matter of fact in recounting noting that she was successful in her attempt to “keep it together”.

During adulthood Mary's strong relationships with her brothers and their families continued. Her mother had developed a chronic illness and Mary was active in caring for her during her last years of her life but stated that she felt like she lost her mother years before her death due to her mother's dementia. The period that followed her mother's death was a difficult time for Mary, made worse by the fact that Mary's father had heart disease and died shortly after her mother. Mary shared the experience of her father's first myocardial infarction. It occurred while she was pregnant with her fourth child. This was significant for her because the baby was premature and even more so because this baby, now grown, was expecting her first child. Mary was particularly worried about this child during her husband's surgery and recovery but chose not to share it with her husband or the other children.

Mary considered her life to be full and was proud of her children and their families. She found contentment in her continued part-time job as her husband's dental

practice. This most recent experience of her husband's surgery was unexpected. She felt as if she and her husband were doing everything right, especially when taking care of themselves.

During the interview, Mary shared her "terror" of waiting for elective surgery. She remembered wondering if her husband was going to wake up in the morning. Mary described the caregiving experience that followed the surgery as physically and emotionally exhausting. She identified her struggle to have her husband adhere to limitations recommended by the healthcare team. She felt like she was well supported by family and friends but continued to feel uncertain about "normal recovery" and was constantly questioning herself. She recently turned to a family friend for advice on how to increase her husband's adherence to the plan of care. She was somewhat bemused that she has had to do this.

She stated that if she "just had some literature to inform me what is normal and what is not", than she would be all right. The uncertainty of her husband's recovery process was an anxiety-provoking experience. In addition, Mary felt that she could not imagine being alone after all this time together with her husband and was overwhelmed by this thought. The potential loss of her husband, in combination with struggling with the feeling of uncertainty regarding his recovery, left Mary in search of knowledge as a way to control the uncertainty of her future with her husband.

Mary's Response to the Pattern Analysis

At the second interview, Mary was given the opportunity to review the narrative and diagram. She was very interested in the pattern construal:

CHILDHOOD	EARLY ADULthood	ADULthOOD	LATE ADULthOOD	PRESENT
<p>“I fought and I screamed and I yelled and I got to go to the local high school.”</p> <ul style="list-style-type: none"> • Middle of 3 children • Loving parent • Fought day boarding school • Wants to be treated like brothers • Close to brothers • Enjoyed alone time with parents 	<p>“I wasn’t going to sit around and not do anything!”</p> <ul style="list-style-type: none"> • Lived at home w/parents; worked for father • Married • Father has MI • 4 children; last baby premature • Educated self on care of premie • Return to work 	<p>“You know, I have been taking care of someone her or there for a long time.”</p> <ul style="list-style-type: none"> • Mother and Father die • Helped take care of M in nursing home • Family vacations every summer • Enjoys leisure time 	<p>“..we started doing all the right things.”</p> <ul style="list-style-type: none"> • close to brothers • Works P/T for husband • Vacations w/ friends • Successful business • Very close grandchildren • Husband w/MI 5 years ago; make lifestyle changes 	<p>We have been together a long time and if he doesn’t get it...well shame on both of us.”</p> <ul style="list-style-type: none"> • Shocked • husband doesn’t know limitations • Lots of support • what is “normal recovery”? • Feels like a mother hen • Seeks advice • Can’t imagine doing this alone • Constantly questioning self

Figure 3. Participant #9 Mary (M): St: Husband F: Father Mo: Mother; B1: oldest brother; B2: brother. S1, S2: sons; D1, D2: daughters. Fr: friends

I have never seen anything like this! I don't remember saying half of this but I know that I did. I agree with you, I do always feel calmer if I know what is going on. If I understand what is happening and why then I can deal with whatever happens. So this has been difficult for me because I can't predict how he is going to be one day or the other. Sometimes he is happy, then depressed. You know, that is tiring.

Mary's Pattern Analysis Summary

Mary's pattern analysis, based on reflecting on the dialogue, the narrative and the diagram displayed an emerging pattern over time. Mary had always been self reliant. This was evident based on the information she shared from childhood, convincing her parents to send her to public school, having her brothers bring home friends from school, advancing her education, working for her father, and educating herself on premature infants. When Mary learned about an experience, she felt a sense of control over a situation. Experiences that appeared to be the most difficult for Mary involved experiencing a lack of control. These included her mother's illness, waiting for her husband to have heart surgery, being unable to share her emotions with her youngest child while waiting after surgery, and currently feeling like she needs to know the "normal recovery" of an individual after coronary artery bypass surgery to better handle her husband's responses to surgery.

The uncertainty associated with her husband's day to day recovery was stressful for Mary as she searched for validation that she was communicating effectively with her husband. Underneath the uncertainty, there was a feeling of being overwhelmed by the idea that she may someday be without her husband, again an experience which she could not control. Mary was struggling to balance uncertainty and control. In the past, Mary had been able to educate herself and create strategies to help her cope with challenges in

her life. She took control of situations as a child, adolescent and young adult. She used information to help her make decisions which helped her manage family illnesses, child rearing and a premature infant. Mary is now struggling with her husband's recovery from heart surgery. This is intensified by the fact that there are no concrete guidelines or absolute answers of what comes next and what to do, Mary continued to seek information to help her feel prepared to face any possible complications or issues but is unable find all answers she needs. Mary appears to be struggling to deal with uncertainty, compounded by the physical and emotional demands of the caregiving experience.

Mary is at a choice point in her life where she is allowing herself to become aware of her response to current and past uncertainties in her life. She was beginning to realize that some outcomes in life are uncertain and that her attempts to control these outcomes may be unavailable no matter how hard she tries to control the situation. She is moving toward an awareness and understanding about her life pattern of being fearful of uncertainty and her need to control the outcomes of experiences in her life. She is able to use the support from family and friends during this transition and seeks new knowledge as she enters this time of change.

The theme of "Fear of the Uncertainty" emerged as the whole, based on Mary's reflections, analysis and Newman's theory. In Young's spectrum of evolution, this placed Mary at the stage of Decentering. With this new awareness around uncertainty and control, Mary has the potential to expand her consciousness by recognizing and accepting the uncertainty associated with life experiences and realizing her inability to control or "fix" every life crises. With this increased awareness of self, Mary has potential to find

new meaning within the uncertainty of life and develop new strategies that will allow her to cope with her need to control challenging situations.

Remaining Individual Participant Narrative Summaries

Katherine's Story: Acceptance as Action

Katherine's Narrative Summary

As a child, Katherine had a somewhat distant relationship with her both her father and mother. Her father “wasn’t around much” and her mother focused much of her attention on Katherine’s brother, who according to Katherine had chronic lung disease. Because of this, Katherine considered her older sister as the individual who took care of her and her other siblings. Despite this, Katherine recalled her childhood as happy.

She met her husband when she was in her late teens and married shortly thereafter. Katherine moved geographically with her husband and experienced an increasing emotional distancing from her family with her geographic move. Although the early married years presented some financial difficulties, Katherine had total confidence in her husband’s ability to take care of her. She and husband were unable to conceive a child. She stated: “We never had any children. We wanted to but I don’t know why it just never worked....you just had to accept it and stop worrying about it. Nothin’ you can do. But we were okay.” Katherine discussed that her brother, who was ill as a child, her parents, and another brother all died while she was a young adult but did not share details on how this affected her.

In their later years, Katherine’s husband had health problems. Katherine was her husband’s primary caregiver after he required a nephrectomy for renal cell carcinoma. He

did well subsequent to this, and Katherine stated she had no difficulty caring for him. With this most recent health crisis, Katherine experienced a different reaction to caregiving. She discussed how the experience has impacted her physically and emotionally and has made her think more about her own health. Despite her statement, “You accept these things more when you older than when you are younger. I have accepted a lot and he is going to need to accept a lot more too”. Katherine was at a critical turning point in her life where she was considering new action related not only to her spousal care needs but for herself. She was becoming aware of her health and the need to take action to keep healthy and make changes.

Katherine’s Response to the Pattern Analysis

Katherine was given a copy of the pattern appraisal to read and was offered the opportunity to add further information, clarify or alter the information.

I guess I have always been someone who believes that you can’t change what is handed to you. You just have to do the best you can. I think I have had a good life. I am lucky to have such a wonderful man and marriage. I don’t know what I would do without him. This had been a lot to handle and like I said, it has made me think more about me. There are some things you can do something about and there are some things that you can’t. I don’t remember saying that about him accepting more but maybe I am right.

Katherine’s Pattern Analysis Summary

Data were examined in light of the Newman’s theory and a reflection on pattern analysis using the narrative and diagram. The pattern analysis revealed that Katherine’s life pattern, from childhood on, was one of acceptance of life situations without questions or concern. Katherine has been able to experience challenges and sustain herself, supported by her husband and their relationship through periods of disruption in her life.

This latest life experience around her husband's illness has Katherine moving in a new direction. She is just not accepting things as they are, rather she is becoming aware of herself, her reaction to the potential loss of her husband and the need to take action to improve her health and that of her husband. In Young's Spectrum of Evolution, this placed her at the stage of Choice. The theme of "Acceptance as an Action" emerged when reflecting on the pattern of the whole.

Bill's Story: Avoiding Action and Expecting the Worst Case Scenario

Bill's Narrative Summary

Bill was just five years old when his father who was in his late thirties, passed away. Bill did not share details of this period in his life other than that his mother did remarry when he was seven to a man who Bill describes as "trash". This man left the family shortly after Bill's mother had two more children. Bill portrayed his mother as a hard worker but did not elaborate on his life at home or on his relationships with his siblings. He did note that his older brother was "like a father to me".

Bill met his wife after his discharge from the military. His military career was cut short by injuries. He reflected, with regret, about his aborted military career. Bill and his wife married young; he was in his early twenties. His wife was in her late teens. They started a family immediately after their marriage. Bill had to return to his job in a local store after he returned from the military, but eventually obtained a job at a local plant where he thought he would remain until retirement. This unfortunately, did not happen. Bill lost his job and his potential for a large pension when he was in his late thirties. He took another job loading trucks at a local plant. He complained that this job aggravated

the injuries he had sustained during the war. At the time of the interview, Bill was still working in this job. When his children were young, Bill's mother died. In his thirties he worried whether he would die or live longer than his father. Now that he was older than his father, Bill shared he was shocked that he "made it longer than my dad did." This was particularly poignant, as one of Bill's siblings was ill with inoperable lung cancer. Bill was not active in his brother's care and stated that the most he could do for his brother was visit him when he could at his other sibling's home.

Bill's late adulthood was dominated by age-appropriate health issues, a deterioration in the relationship with his older son and the failing health of his siblings and wife. When discussing his recent experience as a spousal caregiver for his wife, Bill emphasized how having the help of his younger son, who lived with Bill and his wife, made all the difference in the world. He was able to return to work directly after his wife's discharge home because he knew he could depend on his son being with his spouse during the day. He acknowledged that it was easier to let his wife direct and manage her care than to try to take on the full responsibility for her care. Bill stated he had minimal issues as her post-discharge course has, in his opinion, gone well. "I don't think that I would be doing so good if I didn't have Kevin around or if things didn't go right. It goes by so quick. I know if there was something wrong she would tell me and I could get her to the hospital."

Bill's Response to the Pattern Analysis

The pattern analysis included reflecting on the narrative and the diagram, which displayed an evolution of pattern over time. Bill was given a copy of the pattern analysis

to read and was offered the opportunity to add further information, clarify or alter information.

I really don't remember telling you all of this. I don't usually like to talk; my wife does all the talking. I tend to just be quiet and go with it. You are right or I guess I was right about having Kevin around. If I hadn't been able to go back to work, it would have been a problem. And I think we would have driven each other crazy. I am glad that he is around. It really hasn't been all that bad cuz everything went the way it was supposed to go for once.

Bill's Pattern Analysis Summary

Data were examined in light of Newman's theory and a thorough pattern analysis was performed using Bill's narrative and diagram. The pattern analysis revealed that one of Bill's life patterns, from childhood on, was "expecting and accepting disappointments and underlying sadness". Bill had come to expect a worst case scenario in his life. This expectation was based on his life experiences including the loss of his father when he was five years old; the failure of his mother's second marriage; the loss of his military career; the deterioration of his relationship with his son; his brother's chronic illness and its impact on the family. The expectation of the worst case scenarios was also evident when Bill expressed his surprise that he has lived longer than his father and that his wife was actually doing well after open heart surgery.

Currently, helping take care of his wife was different for him. He uses words like "amazed", "surprised" and "disbelieving" that all went well. New insights and positive life experiences place Bill at the stage of Choice in Young's spectrum of evolution. With the realization that the worst case scenario may not always be the only outcome, Bill has the potential to expand his consciousness and recognize that he does deserve positive outcomes in his life. The theme of "Avoiding Action and Expecting the Worst Case

Scenario” emerged as the whole, based on Bill’s reflections, the analysis and Newman’s theory.

Madeleine’s Story: Putting on a Brave Face

Madeleine’s Narrative Summary

Madeleine’s childhood was one filled with uncertainty. She was the oldest of three girls; her siblings, twins were much younger. Her mother suffered from depression and was institutionalized during Madeleine’s youth. She reflected that her relationship with her mother was neither close nor warm. She was more involved than she cared to be in the care of her younger sisters and mother, especially during depressive episodes.

Madeleine married during her late teens. She had two children while she was in her twenties, a boy and a girl. By all accounts she felt that she and her husband did well. During Madeleine’s adulthood years, her mother had another “breakdown”. At this time Madeleine made a deliberate effort not to be closely involved in her mother’s care. Instead, she made a choice to put her own family life and children first. After Madeleine’s mother recovered, she expressed a desire to have a closer relationship with Madeleine. Cautiously, Madeleine and her mother strengthened their relationship until Madeleine’s mother died in her eighties.

Now in late adulthood, Madeleine’s husband, who is ten years older than she, has had significant deterioration in his health. He had colon cancer, prostate cancer, coronary artery disease and was recently diagnosed with Alzheimer’s disease. Madeleine’s own health problem associated with chronic back pain. Madeleine shared that she felt that it was necessary to remain in top physical shape in order to care for her husband. The

positive aspects of Madeleine's life included her strong relationship with her children and their families and her ability to provide for herself and her husband by continuing to give piano lessons. These aspects have been a source of support and fulfillment

When discussing the current caregiving experience, Madeleine described the post-discharge period as initially "horrible". She was overwhelmed by the time pressures involved in managing her husband's new dietary needs and felt that she could not leave her husband alone. She stated that prior to the CABG surgery her husband did require fairly constant monitoring due to his health status but that she could leave the house to do errands, give her piano lessons or go to church. But now, this had become impossible. For the first time, Madeleine was "feeling her age". She had to adjust her customary routines to be able to care for her husband. She shared that because of the changes in her husband's health there is no chance of recovery of her lifestyle or the way she lived prior to this surgery. With her husband's hip surgery in the near future and his declining cognitive status, Madeleine was tentative regarding her life and responsibilities. The illness experience of her husband was changing her own life experience as well

Madeleine's Response to the Pattern Analysis

Madeleine's pattern appraisal, based on both the narrative and diagram did display a pattern over time. This information was shared with Madeleine at the second interview. She was allowed to add further information, clarify or alter the existing information.

When I look at this last part, I see how overwhelmed I am. I don't think I shared that with anyone else. I *am* feeling my age and it makes me nervous when I think I will have to take care of him more and more. It is almost like I have to take care

of two people: John who knows me and what is going on, and John who doesn't know what is going on.

I talked about my mother a lot, didn't I? For a mother that wasn't around a lot she got in there didn't she? What do you make of that...?

Madeleine's Pattern Analysis Summary

Data were examined in light of Newman's Theory and a thorough pattern analysis was completed reflecting on Madeleine's narrative and diagram. The pattern analysis revealed that one of Madeleine's life patterns, since childhood on, was "Putting on a Brave Face". Her mother's depression and the impact it had on her father were pivotal experiences in Madeleine's childhood. When Madeleine began emotionally distancing herself from negative, challenging experiences she was able to protect herself by not reacting to or becoming involved emotionally. Immersing herself in parenthood and increasing the distance between her self and her mother, Madeleine was able to find opportunity and to continue focus on her life and related interests.

With this recent caregiving experience, Madeleine has had to face increasing responsibilities and the potential of a future dominated by caring for her husband. These challenges have begun to serve as the basis for a new self awareness and a choice point in which she can make changes and take action to sustain her self. As the increasing responsibilities of spousal caregiving continue to inform her life, Madeleine is starting to recognize that she may need to be open to different coping strategies to deal with the impact of her husband's illness other than emotionally distancing herself. This new awareness places Madeleine at the stage of Decentering on Young's Spectrum of Evolution. Madeleine has potential to expand her consciousness by reaching out to her

husband and seeing herself and her own potential during this time of potential crisis.. In doing so, Madeleine has an opportunity to gain a new understanding of this caregiving experience and of the time she has left with her husband while at the same time moving forward with the own life.

Jennifer's Story: Being Cared For Through Life

Jennifer's Narrative Summary

Jennifer was the youngest of six children. When reflecting about her childhood, she stated “everyone took care of me! Our home was very busy and happy.” This time of Jennifer’s life was filled with family, a wide circle of friends and many good times with her older siblings. She recounted “...all the older kids helped out. I didn’t because I was the baby!”

Jennifer’s early adulthood was significant and accompanied by many life changing experiences. She married, had her three children, relocated to her husband’s home state and lost her oldest brother in a war. She shared the devastation that her family experienced with the loss of her brother and emphasized how much her husband took care of her entire family. Jennifer was pregnant at the time with her first child, a boy. She named him after her brother who died.

Jennifer spoke of contentment with her life, with her husband and her children throughout her adult years. She discussed how important it was for her to be at home with her children, much like her mother was with Jennifer and her siblings. The most significant experiences during this time were the loss of her parents and two of her

siblings. She shared the how her husband and children supported her through these losses.

When recounting the last few months, Jennifer shared the challenges she has faced in trying to take control and monitor her husband since his discharge from the hospital. She acknowledged that “I just usually go along with what everyone else wants to do so it was a new experience for me.” She had some difficulty helping her husband understand that this experience of taking control was very hard for her and turned to her son for advice on how to best discuss this issue with her husband. She viewed the caregiving experience as incredibly difficult and had problems sleeping, lost weight and had a hard time balancing her husband’s view that she is over-reactive and the desire to protect him. She found herself thinking about her parents: her husband was the same age her father was when he died; she was the same age as her mother when her father became ill. The most significant emotion for her was the fear of being alone after all the years that she has been with her husband and the idea that having more time with him is a gift.

Jennifer’s Response to the Pattern Analysis

Jennifer’s pattern analysis, based on both the narrative and the diagram, did display a pattern over time. During the second interview, this information was shared with Jennifer and she was allowed to add further information, clarify details or alter the existing narrative. Excerpts from her response are as follows.

I told you I talked a lot! My life was very busy, I guess. I am looking at the quotes on the diagram here and you pick the ones that really fit each of those parts of my life. Did you put me in the center with all those arrows pointed at me for a reason? It makes me look like a pinwheel.

This has been very hard for me and I think that is because other than being a mother, I really haven’t taken care of anyone who was sick. I am overwhelmed by

how constant it is and he is doing very well. I cannot imagine taking care of someone who is really sick. I guess this is what comes with growing up being the baby in the family. I find it very easy just to let someone else make the decisions; it is very hard for me to be the one in charge.

Jennifer's Pattern Analysis Summary

Data were examined in light of Newman's theory and a thorough pattern analysis was completed reflecting on Jennifer's narrative and diagram. The analysis revealed that Jennifer's life pattern, from childhood on, was continuing to live the role of the "baby in the family" which protected her from being on her own. During many of the meaningful experiences of her life including her brother's death, her parents' death and motherhood, Jennifer was content not questioning responsibilities. She acknowledged that she was very comfortable with having her husband be in control, "that has always been okay for us." Jennifer felt fortunate that she had the same marital and mothering experiences that her own mother had and has focused on giving her children the same type of childhood that she knew.

With this recent caregiving experience, Jennifer has had to acknowledge and accept new responsibilities for another that have left her in charge. She has experienced physical exhaustion, weight loss and distress over her husband reaction to her new caregiving role. She admitted that without the help of her son, she would be having a more difficult time being more assertive. Jennifer continues to look for support and assistance from others. She is aware and grateful that perhaps this experience has helped her realize that she is responsible for guiding her husband through his recovery and herself as well. Although overwhelmed she views this as a gift.

The theme “Being Cared for through Life” emerged as the whole. Jennifer faces the challenge of maintaining her newfound voice as her husband’s recovery progresses. Slipping back into a traditional role would be very easy for Jennifer. She is at a choice point and can either continue to seek equanimity and increased respect in her relationship with her husband or move back to a more “traditional” role of being cared for. This places Jennifer at the stage of Choice on Young’s Spectrum of Evolution. Jennifer is moving towards an expansion of consciousness where she can begin to see herself not as the one who is cared for but as an adult with responsibilities and abilities. This new understanding enables Jennifer to explore new opportunities for growth, autonomy, self confidence and respect as a mature, independent adult.

Joan’s Story: Supported through Life’s Crises

Joan’s Narrative Summary

Joan’s childhood was one filled with happy memories of both her immediate and extended family. She enjoyed close, mutual relationships with her friends at school and was active in school programs. She met her first husband through friends while in college. She and her first husband married immediately after Joan graduated. Joan continued to work full time until she had her first child at several years later.

Joan considered her early adulthood years to be incredibly busy and, in retrospect, realized what she thought of as a strong marriage was in actuality not strong. She loved being a mother to her three young children and motherhood was the most significant role in her life. In recalling this time, she stated that as her relationship with her husband

became distant over the years but she did not recognize it. During this same period, Joan experienced the first losses in her life as both of her maternal grandparents died.

As Joan grew older, she settled into what she described as a “typical suburban life”. She continued to focus on her children and home life but the distance between Joan and her first husband increased. Eventually, he left Joan and the children for another woman. Joan was in her mid forties at the time and her children were in their late teens and early twenties. This time was very painful and she remembered herself as being very angry. The one positive thing Joan recounted was the tremendous amount of support she had from her family and friends. Just as she was feeling like she had regained some balance in her life, she had to deal with three tremendous transitions. These included her children leaving home for college, the death of her parents, and dating again. In the midst of these transitions, Joan met and married her second husband.

Now in her late adulthood, Joan considered herself an extremely lucky woman. She has a strong, mutual relationship with her second husband. She remained close to her siblings and their families, although they are geographically separated. Joan considered this a very happy time and is completely enjoying her latest role, grandmother.

Two weeks after her husband was discharged from the hospital, Joan felt like she was coping with the day-to-day care of her husband after his coronary bypass surgery but she was still shocked that he even required surgery. She felt embarrassed that she didn't realize the magnitude of his heart disease, particularly since she was trained as a health professional. She was overwhelmed by how much she did not know and had extreme gratitude that he was alive. She felt as if she was hovering over her husband despite her

attempts not to hover. She was appreciative of family and friends' support which she saw as absolutely essential. Joan was eager to see her husband progress towards resuming their prior lifestyle but was also adamant about educating herself and her family on dietary and healthy lifestyle changes. She had an increasing awareness of what the new "normal" lifestyle would be based on the lifestyle changes that she planned to initiate.

Joan's Response to the Pattern Analysis

Joan's pattern analysis, based on both the narrative and diagram, did display a pattern over time. This pattern appraisal was shared with Joan at the second interview and she was allowed to add further information or clarify existing information.

It seems to me that every time I had something bad happening in my life, I had to focus on something else. Like here (points to early childhood stage), my grandparents died but I was in the middle of having my children. And here (points to adulthood stage), when "X" left I was devastated but then I had to deal with my parents being ill and dying so quickly.

I am completely focused on "B" (her husband). I have a really good feeling that everything is going to be fine; he has done so well. I think, too, that I can really do something about this (husband's recovery). I don't feel like I am bouncing around between things. I am going to do everything I can to help him get better so we can have the rest of our lives together.

Joan's Pattern Analysis Summary

Data were examined in light of Newman's theory and a thorough pattern analysis was done using Joan's narrative and diagram. The analysis revealed that Joan's life pattern revealed a tension between one crisis in her life associated with a second crisis. Dealing with more than one crisis at a time made it difficult for Joan to appreciate the emotional impact of her role in dealing with the crises. Joan recognized for the first time that she could focus completely on her husband, his recovery, her caregiver role and

their future together without competing claims on her time or emotions with support from others and recognition she could get through a crisis. The theme “Supporting Others through Life’s Crises” emerged as the whole, based on Joan’s reflections, the analysis and Newman’s theory.

Joan is appreciative of the support that she has received from her family and friends. What is different for Joan during this caregiving experience was that now she realized she needs to be the primary support for her husband. Her role has changed from “supported” to “supporter”. This has the potential to be very empowering for Joan and she is eager to educate herself and her family about the lifestyle changes that are necessary for continued health for them all.

Joan is at a choice point in her life for expansion of consciousness. It has become very clear to her that she has the opportunity to grow emotionally by taking control. She recognizes that right now she has everything she could ever want in life and she wants to keep it that way. This recognition and the desire to take control place Joan at the stage of Decentering in Young’s Spectrum of Evolution. She has potential for increased awareness of her own inner strength and ability to meet the challenges of life experiences.

Susan’s Story: Living in the Perfect Life: Challenged by Illness

Susan’s Narrative Summary

Susan’s childhood was a happy one, notable for warm relationships with her parents, siblings and extended family. She was very active in multiple school activities and had a close circle of friends. She shared fond memories of childhood pets and viewed

this time in her life as very “innocent and fulfilling”. Susan met her husband in her junior year of college. They dated for five years and married when Susan and her husband were in their late twenties.

Susan viewed her life with her husband as the “All-American Dream”. They both worked as teachers and had three healthy children. Now in her late forties, Susan considered her marriage strong and solid. She was proud of her children who are excelling academically and in sports. Her maternal grandparents, with whom she was very close, passed away shortly before her husband’s surgery. She admitted that this has made her evaluate her own health and in particular her husband’s health as he has diabetes, high cholesterol and still smokes infrequently. Susan felt like she was prepared for the possibility of health issues that would come as she and her husband aged. She was, however, completely “blown away” when she and her husband discovered he needed open heart surgery. She believed that they were both still too young to be dealing with heart disease.

Susan shared that although her husband’s current health experience, surgery and helping care for him has been overwhelming, she was grateful that her husband was diagnosed and treated at such a young age. Her primary concerns at this time included her husband’s recovery from surgery and the challenges of blending her work and caring for her husband and the children at the same time. She felt that the effect of this experience on her children and the enormity that this experience will have on her and her husband will impact the rest of their lives. Susan described that she felt like she could no longer

use her usual coping skills which in the past had included running and going to the gym because she is afraid to leave her husband alone.

Susan's Response to the Pattern Analysis

Reflecting on Susan's pattern, based on both the narrative and diagram, did display a pattern over time. This pattern analysis was shared with Susan at the second interview and she was given time to add further information or clarify existing information. Susan shared the following:

I guess I think that we are still so young but you know what, we're not that young. And I know how much loss I felt, how will my children feel if something happens to me or my husband? I think I have always known that we would have to think about this someday. But, my husband takes care of his health stuff and I take care of mine. I know he should stop smoking but other than that, I thought everything was okay.

Susan's Pattern Analysis Summary

Data were examined in light of Newman's theory and a thorough pattern analysis was done using Susan's narrative and diagram. The analysis revealed that Susan's life pattern was one in which she has been living without significant issues. Prior to her grandparents' deaths, Susan did recall or share any significant losses. The most significant issues in her life, prior to her husband's surgery, were her concerns about his health management, particularly about his smoking but she stated that she was not involved in his health management.

For the first time, other than her mothering experience, Susan found herself caring for another individual. She discussed that at times she felt like she is acting like a mother towards her husband. When asked about this feeling, she reflected that she did not know of any other way to act. Susan was overwhelmed by this new role and was having

difficulty blending her roles as mother, spouse, caregiver and teacher. She mentioned that she did take a week off from work to manage her husband's care but returned to teaching. She believed that her work routine would be helpful. However, she is finding returning to work a challenge given her home life and husband's recovery.

The theme "Living in the Perfect Life: Challenged by Illness" emerged as the whole, based on Susan's reflections, the analysis and Newman's theory. Susan is at a choice point in her life for expansion of consciousness. While she is grateful that her husband's surgery happened early in their lives, there is a sense of hesitancy and fear in accepting the potential changes needed to respond to the chronicity of his disease and the impact of this reality on their "perfect life". Susan's willingness to learn and her openness in trying to accept change in both her and her family's lives places her at the stage of Decentering in Young's Spectrum of Evolution.

Ruth's Story: Caring For Others to Care about Self

Ruth's Narrative Summary

Ruth remembered her childhood as a happy one. She had close, reciprocal relationships with her parents, two brothers and three maternal aunts. She was particularly close to her mother and discussed how this relationship was very meaningful to her entire life. She met her husband in her late teens and they married two years later.

Six months after they married, her husband was drafted and Ruth moved back in with her parents. She was happy with this arrangement and recalled how her husband felt lucky that she didn't bring her mother with them on their honeymoon. She and her husband had two children, a boy and a girl and purchased their first home near her

parents. Her early adulthood was filled with memories and experiences focusing around rearing her children, having both her siblings move away and maintaining a close relationship with her mother and aunts.

The first time that Ruth experienced challenges during her mid-adulthood. At this time, her father, aunt and both of her brothers died. Prior to their deaths, one of her brothers and an aunt lived with Ruth and her husband so Ruth could care for them in their final months. She cared for her mother during the last years of her life as well. Ruth and her husband built the house they live in currently, designed around her mother's needs. "I took care of my mother everyday of my life but it was probably 8-10 years that I really had to physically take care of her. My mother was my girlfriend."

In her late adulthood years, Ruth has strong, reciprocal relationships with both of her children, their spouses and five grandchildren. She and her husband have a fulfilling social life and "do everything together". Ruth discussed how badly she felt when her husband had cardiac surgery. She could not believe that his heart disease was critical. She was angry that in spite of the fact that they were both diligent about diet, exercise and a healthy lifestyle, her husband was still sick enough to require bypass surgery. Although she praised the healthcare team during his recent hospitalization, Ruth voiced distrust in the health care system overall. She disagreed with her husband's thoughts about being discharged to home too early and was adamant that "I know I can be bossy, he knows that too. But, I do know what I am talking about and I know how to help people get better and he is." She appeared angry at her husband's behaviors and associated his slight

depression with his early discharge to home. She is convinced that “he needed me to push him back to feeling lucky to be alive.”

Ruth’s Response to the Pattern Analysis

Ruth’s pattern analysis, based on both the narrative and diagram, did display a pattern over time. This appraisal was shared with Ruth at the second interview and she was given an opportunity to provide further information or clarify existing information.

This makes me look like I have been taking care of people my whole life except when I was a kid. I guess I have. But, you know what, I am good at it. I lived for my mother and no one else could have taken care of her the way I did. She lived to be 94 and all of them were great years.

I don’t think I am angry at (my husband). I don’t agree with that. But for God’s sake, he’s alive, get up in the morning and be happy. I am here, I am not going anywhere and I take good care of him. He needs to start understanding that. I know that no one else could have done what I did. Between Joe, my mother, my aunt, my brother I have taken care of a lot of stuff. I know I helped them. I never did it for me.

Ruth’s Pattern Analysis Summary

Data were examined in light of Newman’s theory and a thorough pattern analysis was done using Ruth’s narrative and diagram. This analysis revealed Ruth’s life pattern as caring for others. From the young age of twenty-one, Ruth has cared first for her children then their children, provided physical and then end of life care for her mother, brother and aunt; and now her husband.

At the beginning of her husband’s health crisis, Ruth did not believe that he was actually experiencing symptoms of cardiac illness and feels guilty that she did not listen to him. It appears that she is now attempting to reconcile the guilt by being over diligent in his care. Ruth’s lifelong experiences of caring for others may also be an

expression of control. Her love for all she cared for is beyond question, but it seems that Ruth needs to be caring for others to feel a sense of worth about herself. Caring for other people keeps these individuals close to Ruth. Ruth manifests a need to be in caring relationships to show how much she loves and cares for the significant people in her life.

The theme “Caring for Others to Care about Self” emerged as the pattern of the whole, based on Ruth’s reflections, the analysis and Newman’s theory. Ruth is so involved in caring and controlling her husband’s recovery that she may not realize that she is near a choice point in her life. This places Ruth somewhere between the stages of Binding and Centering in Young’s Spectrum of Evolution. To move towards an increased awareness may require opportunities for guided reflections and dialogue. Ruth recognizes the role she plays in people’s lives but is challenged by the fact that even when you do everything right, you can still get sick.

Judy’s Story: Always the Supported now the Supporter

Judy’s Narrative Summary

Judy’s memories of her childhood were ones filled with close relationships including her parents, brother, extended family and friends. Judy graduated from high school and went directly into the work force. She met her husband while working at a law firm. He was a clerk there while completing law school. They married when she was in her early twenties. Judy remembered the first years of marriage as a combination of stress, as her husband finished law school, and happiness. Finances were limited but Judy recalled this with amusement noting that “scrimping and saving” brought her and her husband closer together.

Judy had three children in quick succession: two girls and a boy. She stayed at home with the children while they were young and loved this time in her life. She described herself as being in a “traditional role”. To Judy this meant that her husband worked long hours while she maintained their home and cared for their children.

Prior to the current caregiving experience, Judy was starting to feel that both she and her husband were “getting older”. She had lost both of her parents, her children were having children of their own and she felt that as a couple, they were slowing down physically. Judy discovered a lump in her breast which fortunately turned out to be benign. Judy’s mother died of breast cancer and during the diagnosis and treatment of her own breast lump, Judy was frightened that she too may die. This experience supported Judy’s belief that she and her husband are “getting on”.

Although grateful for the support of her children and social peers during her husband’s recovery, Judy stressed that she just wanted to keep her home quiet. She shared that she is “surrounded by her children”. When asked if this is a good thing, Judy stated that “it is all too close sometimes”. Judy was fearful of leaving her husband alone and was “waiting for the other shoe to drop”. She complained of fatigue throughout the day and admitted that she has difficulty sleeping at night. She noted that her husband was restless during the night and when she awoke she was afraid to go back to sleep in case he needed her. She has a “nervous energy” during the day, which in turn contributes to her fatigue.

Judy's Response to the Pattern Analysis

Judy's pattern analysis, based on the narrative and diagram, did display a pattern over time. When the pattern construal and the narrative were shared with Judy she initially did not understand the significance of her pattern. "I don't quite understand all of this. I mean, I understand what you did but how do you see a pattern in there?" When the data was reviewed with Judy she began to see the emerging life pattern.

You know, I am tired. I think that is a combination of growing old and having to deal with P (her husband) not being himself yet. I have always been surrounded by people who supported me; I see what you are saying. Now I have to take care of P and it is very different than I imagined. I love my children and I am so grateful that they are here for my husband and me but I do feel we need a little space just to take a deep breath and get ready to move on. I really feel if everyone can give us a little time alone to let him rest that he would recover faster and I could relax.

Judy's Pattern Analysis Summary

Data were examined in light of Newman's theory and a thorough reflection on the narrative and diagram construal. The analysis revealed that throughout Judy's life she has always had someone caring for her. The caregiving experience with her husband is the first time, other than mothering, that Judy has had to be supportive to another. This is challenging for her and has led Judy to reassess the support that she is receiving from others. For the first time in her life, Judy perceives the support and the offers of help as too much. Most importantly, Judy cannot and does not look to her husband for support during this time. This is a new experience for her as her husband has been her primary support for most of her life.

The theme "Always the Supported now the Supporter" emerged as the whole, based on Judy's reflections, the analysis and Newman's theory. Judy is at a choice point

in her life for expansion of consciousness. As she assumes an unfamiliar role as the supporter, not the one being supported, Judy has become aware of her life in a new way. During this caregiving experience, she has established new boundaries around accepting support. She has placed her focus on supporting her husband and not on herself. Although Judy may not fully aware of her actions, she is moving toward growth as she and her husband continues to experience a shift in their relationship. Judy is at the stage of Decentering in Young's Spectrum of Evolution.

Phase One Summary

In answering the first study question, the findings focused on understanding the individual participants' pattern and movement towards expansion of consciousness. Examining the data in light of Newman's Health as Expanding Consciousness and Young's Stages of Evolution provided valuable insight into each participant's unique pattern at that moment in time.

Phase Two: Data Analysis Across Participants

To answer the second study question, the research protocol outlined by Newman (Newman, 1994) was followed. In Phase Two of data analysis, individual patterns analysis were examined across participants in an effort to uncover recurring themes that reflected the caregiving experience of spouses of individuals recovering from CABG surgery. This was accomplished by using the research protocol outlined in Chapter Three.

Themes

Data analysis across participants examined the unique pattern of each study participant. Shared themes emerged across participants. They were clustered into six

categories and included the following: 1) Disruption in caregivers' roles and responsibilities impacts relationships between the spousal caregiver and spouse and shifts life patterns. 2) Spousal caregivers face coping challenges with changes in lifestyle and response to illness. 3) Spousal caregivers experience vigilance in an effort to ease the uncertainty of the recovery process. 4) Knowledge helps spousal caregivers gain a sense control in the face of uncertainty. 5) Mutual partnership between the nurse and the spousal caregiver in relationship impacts the potential for transformation. 6) Spousal caregivers' awareness of their life pattern gives meaning and offers the caregivers a new perception on life they have left to live. These themes will be discussed and presented individually.

Disruption in Caregivers' Roles and Responsibilities Impacts Relationships between the Spousal Caregiver and Spouse and Shifts Life Patterns

For many study participants assuming the caregiver role presented challenges and opportunities to gain a new understanding about themselves and the dyadic relationship with their spouses. The new demands of the caregiver role presented challenges for these individuals as they began to re-evaluate existing relationships, established new roles and re-examined previously effective coping mechanisms. The subthemes that emerged for this theme included changes of emerging from the dyadic relationship, spousal caregivers assess existing relational boundaries and unanticipated challenge of facing spouses' depression.

Challenges of emerging from the dyadic relationship. With the exception of two spousal caregivers who were in their forties and one participant who had remarried later

in life, each of the caregivers in this study had been married for over 39 years. Most of the spousal caregivers had married in their late teens or early twenties. Their years together produced a relational dyad enmeshment of the study participant and the spouse.

This enmeshed dyadic relationship was so profound for some individuals that there appeared to be an identity shift from “me” into “we”. At time, the “me” was lost in the “we”. The caregiving experience provided an opportunity for the spousal caregivers to emerge from the dyad, make independent decisions and take control over issues that were present before surgery and addressed at times by the spouse. This presented changes in spousal relationships. New challenges presented during the caregiving experience added to the complexity of the spousal caregivers’ roles and extended responses beyond just dealing with recovery at home.

Olga and her husband had weathered many health crises over the years including lymphoma, bacterial endocarditis and strokes. She took great pride that both she and her husband always cared for each other in good time and bad. Olga insisted that her husband be present during the interview process for two reasons. She did not want to leave him alone in another room and she believed that what he had to say would also contribute to the study. Olga stated:

The main person in my life, the most important person in my life...really I am not kidding, we have been married 45 years, is my husband. We like the same food, we like to do the same things, we like everything the same.

Olga and her spouse were so immersed in the dyadic relationship that it was difficult for Olga to separate herself from her husband. She shared that she did not feel

her individual contributions to the study were important enough and that she needed her husband present during the interview to help her explain her caregiving experience.

Ruth, who had been married for 53 years of life shared that “As long as he is home with me, I am fine. I could be in a one room shack as long as he is there with me.” Ruth was very protective of her husband. She firmly believed that she was the only individual who could take care of her husband and pushed for him to come home from the hospital early so she could “get him back on track.” This couple also chose to do the interview together and displayed many of the same mannerisms that Olga and her husband expressed during the interview. For example, they completed each other sentences, corrected each other about the accuracy of life story memories and kept close physical contact with each other during the time the nurse researcher was in their home. Both of these couples were so immersed in the dyadic relationship such that they could not see themselves acting independently from of their spouse.

Both of the male spousal caregiver participants, Jim and Bill, relied heavily on existing, predefined roles and relationship with their recovering spouses. Jim, married for 45 years, took comfort in his relationship with his wife and the definition of self that emerged from within that relationship. He acknowledged that his wife is the “disciplinarian” in the family and he was comfortable with this. He did not see the need to be independent in his decision making before or during the caregiving experience because his wife was and is the primary decision maker. He actually returned to work two days after she returned home, stating “I just do what she wants me too and I don’t ruffle

her feathers. That is the best way for me to be and that has always worked for us...since way back in high school.”

The one notable event that suggested Jim’s desire to have an expanded sense of control for decision making outside of the dyadic relationship was that he did not tell his spouse that he was participating in the study. He was the only participant who chose to meet outside of his home. He came directly to an outside location after work to meet for the interview. He also shared that he had not told his employers of his wife’s surgery. He did not want to discuss the experience with them or have it affect his ability to work. His participation in the study suggested his need to discuss the experience as an individual but without his wife’s knowledge or participation.

Bill, the other male spousal caregiver participant returned to work directly after his wife’s discharge to home. He stated “it is easier for me to let her tell me what to do and when to do it.” He relied heavily on one of his sons for caregiving assistance while he was at work during the day. “He was a big help. He was here so I could go to work and then I would come home and take over. She was pretty much taken care of. She knows what she wants all the time.” Maintaining his traditional or historic role in the dyadic relationship was comforting for Bill. He has been married to his wife for nearly three-quarters of his life and the idea of challenging established roles seemed too much for Bill to undertake.

Another participant, Katherine, married since her late teens, was in her relationship for 50 years. The couple was unable to have children and lacked family who

live locally. Through the years they developed a very interdependent relationship.

Katherine stated:

So mostly my husband and I take care of each other; we are fortunate that we got up in years before all this stuff arised. See, I am from the South like I said and he has lost a lot of his brothers and sisters and things so now it is mostly just the two of us. We have no children but you know we made it through all right.

Madeleine, another participant, faced additional challenges during her caregiving experience as her husband who was not only recovering from heart surgery but also had a declining cognition due to Alzheimer's' disease. She stated "... I feel like I have to think for the two of us and I tell you, that is hard work." Because of her husband's Alzheimer's' disease, Madeleine had unique challenges and struggles ahead of her. In addition to the changes in Madeleine's role and responsibilities related to this caregiving experience, she faced the long-term and permanent changes in her relationship with her husband as his health continues to deteriorate. Madeleine was aware that these changes in his health and their relationship would have a profound impact on her.

Spousal caregivers assess existing relational boundaries. The recognition that previously effective coping strategies and relationship roles were less effective or fulfilling within the new caregiving role offered many of the spousal caregivers an opportunity to reassess their pre-existing relational boundaries with their spouses, family and friends. With this reassessment there was also a shift in the interpersonal dynamics of communication between the spousal caregiver and spouse. This was manifested by participants' description of the flow, direction and focus of the dialogue between the caregiver and the spousal care recipient.

Although most of the participants considered their relationship with their spouses as strong and mutually rewarding, some of the participants, the female spousal caregivers in particular, recounted how they needed to speak with friends or family members to find new ways to communicate with their husbands specifically around issues of care and self limitations. The new burdens associated with the caregiving experience were such that the spousal caregivers often expressed a need to change their way they related to and communicated with their spouses, particularly if they needed to take control of a situation. Mary shared the following:

One of our friends who is very much like Stan personality wise and has a wife who is very much into nutrition was over and I asked him “Joe, how do you handle it when she tells you what to eat all the time?” And he said “Well, I don’t like it but I know she is saying it to me for my own good.” So I asked him, “How do I tell Stan, what do I do?” And he said, “You be very firm and you say this is what you are eating or doing and this is what you are not eating or doing. He is going to give you glaring looks but he knows you are doing this because you love him. So don’t be intimidated by that.” And you know, he was right, that made me feel stronger. We have been together for a long time and if he doesn’t get it....well shame on both of us.

Jennifer described how she relied on her eldest son for support as she stood her ground and tried to tell her husband what he could and could not do. Her responses, based on her perceptions of what was in his best health interest, displayed a new way of communicating and taking charge that was different from past expressions.

Well, I stood my ground which was a little difficult. But I knew it was in his best interest and that I had to do it. He wasn’t happy about it. I am glad I did it but it was hard to be firm. My son really backed me up and that was helpful. I just usually go along with what everyone else wants to do so it was a new experience for me.

Judy, on the other hand, assumed the unfamiliar role of being the supporter instead of being the one supported. She discussed being overwhelmed by the implications

of her husband's recent health crisis, her role in his recovery, and the anticipated uncertainty associated with change. During this spousal caregiving experience, her first caregiving experience outside of parenting, she established new boundaries around what she would accept herself as appropriate support. She has felt overwhelmed and unfocused by others surrounding her as she felt too much support and too much intrusion was not as helpful as it had been in the past.

I have always been surrounded by people who supported me; I see what you are saying. Now I have to take care of P and it is very different than I imagined. I love my children and I am so grateful that they are here for my husband and me but I do feel we need a little space just to take a deep breath and get ready to move on. I really feel if everyone can give us a little time alone to let him rest that he would recover faster and I could relax.

Assessing relational boundaries within the context of caregiving enabled spouses to talk about how they had learned new strategies for getting a valued point across to their loved one. If their spouses argued or refused to do what the spousal caregivers were asking them to do, the caregivers would stress to the spouse that he or she had been told to do whatever they were doing by the healthcare team. Susan shared the following:

You know you get that list from the nurses about when to call the hospital. You know, if he has a fever, if he can't catch his breath. He would get so irritated that I made him take his temperature everyday. I would just yell right back at him "They told me to do this. Do you want to get sick again?"

Mary described how her husband became angry when she wouldn't let him go check on his boat which was docked in the local harbor.

Periodically he will say "Can't we just do this or go there" and I have to just talk him down. He wants to go down to the boat. But I am so afraid of that ramp and at low tide it is so steep. So he is ready to move a little faster than I want him to. If he doesn't listen to me at first I show him the list that we got at the hospital and I tell him that he has to 'whatever' because that is what his doctor wants. He usually listens to that, not me, but he listens to that.

Within the caregiving experience, the spousal caregivers felt they were put in a position to assume a more dominant role in the day-to-day management of their spouses' recovery. This shift in power and role function was uncomfortable and unfamiliar for many of these participants. Discussing issues around communication with their spouses through a third party, either a friend or family member, was both validating and strengthening. For many of the participants, even though they accepted the challenge of communicating in a new way, some still needed validation and permission to alter their pre-existing modes of communication with their spouses.

Spouses were also aware of the need to ask for assistance where it was previously not warranted. Participants acknowledged that they were unable to perform activities that prior to the caregiving experience were considered easy to manage. The spousal caregivers and the care recipients had to look outside their established dyadic boundaries for support around things such as assistance with caring for their recovering spouses when the caregivers needed to return to work, day to day management of the home and understanding the often detailed instructions involving the post-discharge care and medications. These changes were particularly difficult for the many of the participants who took great pride in their independence as a couple despite their age and functional limitations.

Unanticipated challenge of facing spouses' depression. Many of the spousal caregivers discussed how depressed their spouses became after returning to home from the hospital. For many, this was an unanticipated aspect of recovery. Participants described feeling ill prepared to deal with their spouses' depression particularly because

they were so relieved that their spouses had survived the surgery. Ruth, who has pushed for her husband to come home early from the hospital in order for her to care for him, shared: “He also got a bit depressed and I said to him ‘What are you depressed for? You are lucky to be alive for God’s sake.’ I said ‘You got me, you should be happy!’”

Likewise, Olga was very concerned about her husband’s depressed mood and inquired about anti-depressant medication for him. She mentioned that her husband refused to discuss the issue and believed he was doing well. She challenged him saying: “No, you are not and I am the one who has to live with you and see you so upset all the time.” She recognized that he wasn’t the way he used to be emotionally stating “That is really not like him at all that is why it concerns me so.”

Katherine noted “You know he would get uptight with me sometimes, aggravated with me if I didn’t do something fast enough or quick enough. It upset me. He said I didn’t have everything just ready for him when he got home.” She discussed how this was very unlike her husband and noted what made the experience even more difficult for her was his getting aggravated with her and his recovery alternating with waves of sadness. She felt ill prepared to deal with these new, significant and shifting emotions being expressed by her husband.

Mary’s account mirrored other caregivers. She too was concerned about how depressed her husband was on one day and then not depressed on the following day. She expressed feeling the need to do something for him but she did not know what to do to help.

You know like yesterday, he had a tough day with depression. And I thought, well I suppose this might happen. Well, I didn’t know if this generally happens or is

something new wrong? Should I call the doctor, am I doing something wrong; is it his heart or are the medicines doing this?

The challenges of caregiving were enhanced by skeptical and emotional responses of the spouses to surgery.

Spousal caregivers face coping challenges with changes in lifestyle and response to illness

The subthemes that emerged for this theme included spousal caregivers face challenges related to altered perception of personal space, Adapting long-held routines to accommodate caregiving, new caregiving responsibilities led to physical exhaustion and an awareness of emotional constraints and a search for new ways of coping.

Spousal caregivers face challenges related to altered perception of personal space. Many of the spousal caregivers chose to limit visits in their homes from individuals other immediate family members and activities outside of the home. This limited interaction with others could be interpreted as an aspect of the vigilance that the spousal caregivers felt in regards to caring for their spouse. In the process of limiting interaction however, there was recognition of how important socialization was to them. Madeleine noted that in addition to a diminishing social circle that existed prior to caregiving experience due to the deaths of many acquaintances, it was increasingly difficult to leave her home with her spouse for any social visits since the returning home for the surgery.

It is hard to go out now a day because he gets uncomfortable when he is in different places. So our friends come to us when they can. We all have our own problems so it is hard to expect anything other than their company.

Prior to surgery, most of the study couples led very active social lives. Many participated in card clubs, dining out with friends, neighborhood activities and church. The younger spousal caregivers with children were active in school activities and had fulfilling social lives. During the caregiving experience, the spousal caregivers felt unable to partake in these activities for fear on either leaving their spouses alone or exposing their spouses to illness. Susan stated:

I feel badly that my kids are getting shuffled around because I can't make it to all of their after school stuff. I literally go to work and come right home. I haven't even made it to church. You would think of all the places I wouldn't miss!

My friends have been great but I feel like I need a girls' night out, you know what I mean. A night for me, just a little bit.

The caregivers were often restricted from those activities outside the home in order to "watch" and monitor their spouse's health.

Adapting long-held routines to accommodate caregiving. Many of the spousal caregivers discussed how they changed where they slept so they could keep a more watchful eye on their spouses. They discussed how the day-to-day living demands of caring for their spouses required them to rearrange certain rooms in the house. Examples of this include moving bedroom furniture into the living room area, no longer eating in the dining room because the table was now covered with paperwork and medications, sleeping on the couch in order to be near their spouses; and restricting outdoor activities to their own property instead of going out into the community.

Olga shared the following:

And he said 'I can't sleep in that bed' and I said 'Okay' and I made up the sofa for him. I put a pad on the bottom because first you know he is sweating then he is freezing. So I fixed it all up with pillow because you know he had to sleep on

his back with his feet elevated. So he did go to sleep for the rest of the night, no wait you told me you woke up again and watched the TV for about 15 minutes and then went back to sleep again.

Mary described how she and her husband had to spend time in the basement of their home because the heat and humidity had been too much for her husband. “You know, this house is not air-conditioned and we are looking into having that done. So we are thinking maybe next year. We always go down in the basement.” Mary also disliked the fact that her entire dining room table was covered with paperwork and medications. She and her husband no longer ate at the dining room table. They took their meals either in the kitchen or in the living room, something they had never done before. The impact of the spouse illness moved beyond the individuals and actually altered the physical space of the couple

New caregiving responsibilities lead to physical exhaustion and an awareness of emotional constraint. Nearly all of the spousal caregivers shared a sense of physical exhaustion. They spoke of changing their usual sleep routines to accommodate the needs of their spouses. This included changing where they slept, waking frequently during the night to check on their spouses, and altering the times that they normally went to bed and rose in the morning. They found that these changes in their sleep routines did not leave them feeling well rested. The spousal caregivers also reflected on how the constant vigilance and worry were exhausting. They discussed how there was never a “down moment” to relax and catch their breaths.

Katherine recalled how she felt like she “never stopped” in the first few days after her spouse came home from the hospital. That combined with being unable to sleep well at night had left her exhausted.

And running up and down the stairs...they said he could go up and down the stairs. We have a family room down stairs and I was up and down those stairs so many times. It was unbelievable, but I done that and we made it through it all right. As I said a few nights there he wasn't breathing too good and we slept in the living room. And, I slept on the couch, what little time I slept because he said if he sat in the recliner he could breathe better. But then he said I am going to try the bed again and we went back to the bed with a higher pillow which was better for him. And I just listen out for him at night...

Olga became very emotional when she shared the story about how she almost drove off the road after a doctor's appointment.

I think I was more tired than he was. The worst experience was when we were driving home from one of his appointments and I fell asleep at the wheel of the car. He was in the back seat thank God because they told us that he can't ride up front for the first month. We were not too far from home and I just completely dozed off. He yelled at me just as we started to go off the road into the ditch. I managed to get the car back on the road but that really shook me up. I was so afraid that I had hurt him. After all that then I kill him in a car crash or hurt his chest. I just have not been able to hit a good, deep sleep. I keep waking up to check on him. You would think I would be exhausted from doing all the work around here during the day. I guess I am but I just cannot sleep.

Madeleine discussed how she had to alter her normal sleeping cycle in order to give her spouse his medications on time or be awake when he was so she could watch him.

I am not a morning person either and I had to make sure that I got up so he would get all of his meds. Well that was all day. But I was dragging at the end of the day. It is just very hard to coordinate what he needs, my piano lessons and any free time at all.

Jennifer had not slept well since her husband had come home from the hospital and was starting to see physical changes in herself related to caring for her spouse.

I think I have lost some weight because I am so concerned with what he is eating that I don't think I have been eating right myself. But that is okay, I needed to lose a few pounds. I am very tired. I think that even when I sleep I am not sleeping deeply. I think I still have that little bit of feeling left over that he is not going to wake up in the morning so I wake up a lot and check on him. And when he naps I sometimes still watch to see if he is breathing, just like I used to do with my children when they were babies.

Many of the spousal caregivers were reluctant to show their spouses just how worried and concerned they were about their spouses' diagnosis, surgery and recovery from surgery. This emotional constraint was also evident when the spousal caregivers discussed dealing with their spouses' postoperative depression. The spousal caregivers were reluctant to share their own emotions with their spouse because of the potential of upsetting their spouses.

Jennifer compared this caregiving experience with her early days of mothering. She was very reluctant to share this with her husband as she feared the analogy would upset him. She discussed how irritated he would get with her regarding her vigilant behavior. He felt she was over-reactive and protective. She had a difficult time not sharing with him how upsetting those comments were to her.

Mary shared that she had lost her father when she was pregnant with her fourth child. This child was now grown and pregnant with her first child. Mary was overwhelmed with memories of being pregnant and losing her father but was reluctant to share the emotion with anyone.

Everyone was just trying to make it through to the operation; I didn't want to talk about everything that was going through my head about my father and how he didn't make it. I didn't want her to think about what happened to me when I was pregnant with her so I just kept quiet.

Sarah shared that she felt that she had kept herself emotionally “in check” during time that she learned that her husband needed surgery through the present time. When she was discussed her experience Sarah described the need to be in control of her emotions so that her family would not become upset. When she talked about crying and letting her emotions out at any point she shared the following.

You know what, no. I might not of; I think I always stayed right at okay. I think I thought it would be silly to go crazy over it. What good would it do any of us? It wouldn't be good for the kids; it wouldn't be good for my grandmother, it wouldn't be good for my husband; it wouldn't be good for me.

A search for new ways of coping. For many participants coping strategies that had previously worked for the spousal caregivers in the past were no longer effective within the new caregiving experience. Some of the spousal caregivers struggled to find new approaches to deal with the strain of caring for their spouses in a new way giving way to their perceptions of the burden of the caregiving experience. Because of new responsibilities and burdens associated with caregiving many of the participants were left without effective stress ways to manage their stress. Limited quality time alone, limited access to relationships and activities outside the home and feeling unprepared for the day-to-day demands of caregiving during the spouses' recovery process compromised the spousal caregivers' ability to cope with the added challenges of their spouses' recovery at home.

Susan, one of the younger participants, recounted how she has felt unable to go running or go to the gym due to because she was afraid to leave her husband alone. She had not been successful in finding a different way to relieve her stress during the timeframe of the study. Similarly, Madeleine, who found great comfort in teaching piano,

felt she was unable to leave her husband and go to her students' homes. Prior to her husband's surgery, Madeleine had transitioned her piano lessons to her students' home because of her husband's declining cognitive abilities. She recounted how leaving her husband at home and going to her students' homes was often the only time that she had for herself.

Spousal Caregivers Experience Vigilance in an Effort to Ease the Uncertainty of the Recovery Process

During the first few weeks at home the spousal caregivers, for the most part, felt well informed regarding medications, limitations around activities and knowing when to call their healthcare provider. What the caregivers were not prepared for was the unevenness of their spouses' progress or recovery over the first weeks of recovery at home. Participants discussed their surprise regarding the physical demands placed upon them, the time commitment involved in caring for their spouses and the lack of knowledge associated with postoperative depression for the recovering patient. Ruth discussed how the variability of the recovery was extremely taxing on her and on her spouse.

You know what was hard for us? One day you take a step forward the next you take a step backwards and you think "hey, I am going backwards that's not good". Why is that happening and there is no one around to tell you what is going on. I keep telling him that I am giving him 6 months to get fully recovered. He would have a bad day and I would say "look forward to tomorrow, it will be better." And half the time I would feel like I had given it all to him the day before and had nothing to give the next day.

The spousal caregivers shared how in their attempts to be successful caregivers, despite the uncertainty of the recovery process, they often became vigilant in the

monitoring and care of their spouses particularly in regards to level of activity, interactions with other people, and adherence to recommended restrictions. Caregivers repeatedly discussed the fear they experienced when leaving their spouses alone. Leaving their spouses alone was viewed as an opportunity for something to go wrong with the recovery process and potential for the spousal caregiver to miss an opportunity to ensure the recovery continued to progress in a positive manner.

Mary worried and had difficulty imagining herself assuming a dominant role in the caregiving relationship. She shared the following:

I did on the other hand worry a lot about him doing too much when I am not here. I am worried that he will try to lift something; I know I am being a mother hen here. I try not to be but I can't help it. I know him and I know that he is going to try to push.

Judy described her fear of leaving her husband alone at any time. Because of this she was vigilant and reluctant to sleep at night "in case something happened" to her husband and her husband might need her. She talked about how she has restricted visitors in their home. She also talked about her attempts to keep the home quiet for her husband so she could limit things that could compromise his recovery.

I try to keep the house quiet and warm for him. I only let a few people visit each day. It is just too much to have this house filled with the kids and all of our friends. God, the last thing he needs is to catch something from someone.

Sarah, one of the younger spouses in the study, discussed how she cannot easily stop checking on her husband or asking him how he is feeling:

You know what has scared me the most. When we go to bed at night, I can hear his heart beat. It is loud and it scares me. And I have to keep asking him almost every night "are you okay, are you okay?" It really frightens me that I am all of a sudden not going to hear that heart beat. I never noticed his heart beat before.

Joan, a participant who remarried in later life and is a nurse, discussed her awareness of how she hovers over her husband:

I don't want to hover; even when I make an effort not to hover...I am hovering. I feel embarrassed that I didn't realize the magnitude of his heart disease before all this happened and now I don't want to miss a thing.

Another caregiver, Olga, feared that leaving her husband alone would result in him doing more than she he should. She commented:

You know I just don't like to leave him for any time at all. I turn around and he is trying to do all these things that he is not supposed to do and he tries to do too much at times.

She expressed a need to help him stay within the boundaries of what she perceived as an acceptable level of activity. This need to monitor the recovering spouse appeared across nearly every participant.

Katherine described how worried she was about her husband and how she tried to help him, particularly during the hours of the night. She shared the following:

It was kind of like hard and I was worried about him. I wasn't sleeping naturally and when I did he would start to cough and I would have to get up and run and get him water and rush around and get his pillow. Every time that he wanted something I would jump up and get it for him. You know, we have a tendency to overdo it sometimes. I do that. I helped him do everything I could possibly do. I guess I baby him.

Jennifer stated, "I am glad the operation is over but I still feel like I have to watch him all the time. I don't think he understood that I was bossing him around for him, not for me." She went on to say:

When we left the hospital, the nurses told me that I needed to be comfortable with telling him what to do. I had to call if things weren't going right, like if he had a fever or if he heart raced. And I rally had to watch him so he would stick to the restrictions like no driving, no lifting.

Knowledge Helps Spousal Caregivers Gain a Sense Control In The Face Of Uncertainty

For Mary, not knowing what challenge each day would bring proved to be very frustrating. In the past Mary had always been able to educate herself about different issues in her life. She discussed her experience of having her fourth child born prematurely and how she read everything she could about premature births. This helped relieve her fear associated with this challenge. With this new caregiving experience, Mary has felt uneasy with the fact that she did not know what to expect from her husband each day and nor could she adequately prepare herself for the unanticipated challenges she would experience throughout the recovery period and beyond.

I think I would have liked more specific instructions about what to expect. There was so much paperwork, if I could have had one sheet or a card to go to and say “Okay, that is supposed to be happening.”

The spousal caregivers were often shocked at how little time they had for themselves often because of the vigilance that many of them felt in caring for their spouses. They discussed how they had to rearrange their own long-held daily schedules in order to meet their spouses’ needs. The spousal caregivers were amazed at how much time it took to care for their spouses; for example learning and preparing meals to meet new dietary restrictions, making sure that their spouses were following exercise restrictions and trying to perform their presurgical responsibilities around the home.

Madeleine in particular was overwhelmed by the new dietary restriction and the time it required to make meals that met those restrictions.

You can’t use any prepared foods of any sorts. Any crackers or canned, it is all filled with salt. I was going to use a can of tomatoes but it had too much sodium in it. So everything you do has to be from absolute scratch. And that is time consuming. He was on a diabetic diet and a heart diet and a Coumadin diet and

low salt and low fat. It is miserable, it is so much. I have to start from scratch to make sure everything is salt free and make extra trips to the grocery store which is really hard to do now.

Olga shared the following about relearning her husband's medications, and the demands of making sure she adhered to the appropriate times and dosages and determining if her husband was still taking the medications he was prescribed before the surgery.

I lay out his old pills, his regular medications and then he adds in his new medications from the surgery. I think the Coreg is 3.25 mg twice a day. Sometimes it is hard to keep all the doses and the times right! Oh I don't know...

The time limitations also required the spousal caregivers to make choices as to what they could or could not accomplish. Some of these choices necessitated distancing themselves from other relationships in order to have the time and energy to care for their spouses.

And my mother is dying in the nursing home. I think I told you about that when we were in the hospital. She got sick about 5 years ago. That has taken a lot of my time too. But I put her on the back burner and have focused on my husband. She has had a long life and whatever happens, happens at this point. She has cancer and they are trying to do whatever they can to manage her pain. She is on Morphine now so I can't imagine that it will be much longer. I can't take care of her and my husband too so I had to make a choice. There just is not enough time in the day.

The younger spousal caregivers had concerns regarding their children. These issues focused on quality time with their young children, managing school and extracurricular activities, and attempting to keep a "normal routine". Sarah felt she could not be everywhere at once because she did not have the time.

I have to say, he is taking care of himself; a lot of it is him. I don't know if part of it is that I don't have time to take of him. I don't think he minds. He wants to get better, he is strong and again, I am so busy.

The younger spousal caregivers were also concerned about returning to work and the implications that this had on caring for their spouses and their own concentration in regards to their professional responsibilities.

*Mutuality within the Partnership of the Nurse and the Spousal Caregiver Relationship
Impacts the Potential for Transformation*

Living “in” the theory or research as praxis fosters the intentional presence of the nurse and promotes a mutual reflective process during the dialogue. Spousal caregivers shared meaningful relationships and events in their lives with the nurse researcher. Throughout the research process, spousal caregivers acknowledged recognition of pattern in their lives with participants expressing a desire to take action and make changes in their lives based on reflections with the nurse researcher.

For the spousal caregivers, the intentional partnership formed with the nurse researcher during the research process presented an opportunity for the spousal caregivers to dialogue and focus on themselves. Many found this chance to reflect on their lives was empowering, motivating and illuminating. The presence of the nurse researcher within praxis became a vehicle for the spousal caregivers to look within themselves and gain a new awareness of what they were experiencing and the changes introduced into their lives by their spouses’ surgery. By concentrating on what was most meaningful to the study participants and facilitating the process of pattern recognition, the nurse researcher assisted these individuals in gaining new insight into their life pattern and responses to the current changes in their lives. This recognition of pattern by the spousal caregivers opened up the possibility of transformation and expansion of consciousness.

For many of the spousal caregivers, the opportunity to share their life experiences during the interview process was one of the first times they had to look at the impact of the caregiving experience. The interview process was an opportunity, although a limited one, for the spousal caregivers to focus on themselves. The interview process was, for many participants, an opportunity to express ideas and concerns in an open environment that permitted a personal unfolding. The participants were able to reflect on significant and meaningful events and people in their lives and on the impact that past and current experiences have had on their pattern of responding. Some of the spousal caregivers became very sentimental over these events and people from their past.

One of the participants, Mary, shared that she had not cried the entire time since hearing that her husband needed surgery. But as she spoke during the interview and reflected upon her experience, she began to cry:

I thought (starts crying)...we have been married for 39 years, I am so sorry...: No, I am okay. But I kept thinking that we have been married for 39 years. What am going to do if something happens to him? I can't believe I am crying now, now that he is home and doing better.

Sarah became emotional when she shared how she felt during the time that her husband was having surgery and during his hospital stay.

You know when he was in the hospital I said to my mother "Mom, I don't know what is wrong with me but I am not nervous." (Sarah pauses, start to cry, wipes her eyes and tries to smile I remember he was so scared because something like that had never happened. It was hard to see him so nervous. It is like a good thing. I remember him crying after he got his report that his heart was so bad. That was the first time I had ever seen him cry. It just breaks my heart now to think of him like that. Now here I am crying.

Susan shared how she held her breath while her husband was in the hospital. She stated that now, during the interview, two weeks after her husband came home from the hospital, she feels like she can breathe.

I really felt like I couldn't get a deep breath. I have felt like something is going to let go but I don't know what. Until today, this made me cry. Maybe that is why I am getting choked up now; maybe this is good for me.

The mutual partnership created with the spousal caregivers was also a transformative experience for the nurse researcher. Witnessing the moment of pattern recognition and the potential for expansion of consciousness in these individuals was rewarding in a variety of ways. By recognizing that each participant was a unique individual with a unique life story and readiness for growth, the nurse researcher through her intentional presence and grounding in Newman's Theory was able to connect and move with each of the caregivers through the process of pattern recognition. There was an increased awareness of the importance of nurturing the relationship between the nurse and the client as well as an improved understanding of how little time is required to establish that relationship. It is within that relationship that both nurse and client can find new meaning, choice and movement towards expansion of consciousness.

Spousal Caregivers' Awareness Of Their Life Pattern Gives Meaning And Offers The Caregivers A New Perception On Life They Have Left To Live

The majority of the spousal caregivers' lives had come to be defined as part of a spousal dyad. The idea of living without their spouses was frightening and inconceivable to the participants. Taking the time to remember their lives with their spouses made the spousal caregivers more aware of the time left to live. Many of these individuals were

married for well over half their lives and discussing the possibility of losing their spouses made them quite emotional. Reflections on pattern and experiences of their lives and caregiving also provided an opportunity for these individuals to focus on themselves outside of the caregiving dyadic relationship. In doing so, the participants were able to focus on their own mortality and the impact of their life experiences on their present and future. The subthemes that emerged for this theme included years together impact attitude regarding caregiving experience, facing one's own mortality, focusing on the meaning of the present, seeing the past informing the present and the overall impact of past caregiving experience on self.

Years together impacts attitude regarding caregiving experience. The two younger spousal caregivers reflected how their spouses' surgery and recovery was in fact an opportunity to appreciate each other. These younger spousal caregivers were thankful that their spouses were young, otherwise healthy and able to make lifestyle changes that would prolong their lives and their time with their young families. The younger spousal caregivers also reflected on how much more difficult the caregiving experience would have been if they and their spouses were older.

Susan looked at her husband's surgery as a chance to start over. They were both young, healthy and had the financial means to make the lifestyle changes they needed to make. She understood that her husband's younger age was a significant factor in his recovery. She shared how they both felt incredibly young in comparison to the other couples at the hospital. Susan noted that being younger has made the caregiving experience easier for her:

I am so thankful that I am in pretty good shape. This has been a very tiring experience and I can't imagine doing this when I am 70 or 80 years old. That first week at home was nonstop go and if I was older or had my own problems I don't think either of us would have done so well.

Sarah reflected on how different her husband's experience was from the older patients in the hospital.

I remember those older people in the heart unit. And I remember thinking I am so glad this happened now because he is in a better place to take care of himself. He is stronger; the turn around time is quicker after the operation. He really stood out at the hospital. He was walking by himself; the other men were using walkers. He can exercise earlier and other wise he is healthy.

Sarah was very emotional when she talked about the idea of going through this caregiving experience later on in life, as compared to being in her forties.

It must be so scary for them and their wives. You know they have been married longer so it means more to them to have them around. I mean, if he had gone, I would have been devastated. I don't know if my heart would have been as broken as these older ladies. We have been married 15 years. It wasn't until I was married about 10 years that I started to realize that this was it, I made the right choice. So I am sure that when it happens the heart break will only get worse the longer we are together. It makes me appreciate my life.

For some of the older spousal caregivers, the caregiving experience was an opportunity to assess how they and their spouses felt about their remaining years. Some of the caregivers were surprised at the different outlooks that they had from their spouses. Katherine shared the following:

I think I appreciate life more than my husband. Because...I don't know if I am saying the wrong thing. You know if he dies tomorrow, he is ready. But I think I appreciate life more than he does, because life is more important to me. I don't know it that is a good thing or a bad thing (laughter)! But that is the way it is.

For the older spousal caregivers, the surgery and their spouses' recovery made them reflect on improving the quality of life left together.

Olga: But you know what we have to do is take time for ourselves and relax and let it be okay that we are doing that. We haven't managed to be able to do that yet have we (turns towards husband).

Spouse: Well we better hurry up and figure that one out.

Olga: You are right about that (laughing). Neither one of us is a spring chicken!

Facing one's own mortality. When the caregivers took the opportunity to reflect on their own aging process and changes in health patterns they were often surprised to realize that they too were growing older. The spousal caregivers seemed to feel there was incongruence between their chronological age and the age they felt they were. Jennifer shared her feelings about realizing her age and the implications it had on the idea of her own mortality.

Having something like this happen also makes me realize that we are getting older. I still feel like I am in my 50's then I see my oldest son who IS in his 50's and it always surprised me. Do you know what I mean? So to have someone tell you that your husband has a problem with his heart when he has never really had any problems is, well, it is shocking. It is a very strange thing when you realize that you are almost as old as your parents were when they died. To have all this happening now makes it a bit more frightening.

Susan, one of the younger spousal caregivers, reflected on the following:

I guess I think that we are still so young but you know what, we're not that young. And I know how much loss I felt (when her grandparents died), how will my children feel if something happens to me or my husband? I think I have always known that we would have to think about this someday.

The study participants were all relatively healthy. Only one participant had significant health issues, but the experience of having their spouses undergo open heart surgery made the spousal caregivers more aware of their own potential health problems. Katherine described it this way:

Well, to tell you the truth, I got a bit depressed. When I learned about my husband's heart problems, I think I had more heart pain than he did. It made me think about myself. Well, I haven't had a physical....you know it made me think

about myself. I put that stuff off. He is always preaching for me to take care of myself which I don't do. But now, well this makes you more aware. These things that could happen.

The spousal caregivers spoke of being frustrated about following all of the recommendations given to them by their health care provider in relation to diet, exercise, lifestyle management and feeling like they were unsuccessful. Many of the participants and their spouses looked at the need for surgery as a failure to meet their health needs.

Olga discussed how frustrated she was in regards to doing everything as recommended and still not avoiding illness:

And you know it is hard because all these years we have tried to do everything right. We took good care of ourselves. The nutritionist that came here was amazed by how well we ate. We were really active. The doctor said that is we hadn't been so good with all that that he probably would have had a heart attack a long time ago or he would be dead.

Ruth was very focused on the fact that all of her husband's lab work had been normal and at his last physical exam his physician had told him he was in great shape.

Reflecting back I am kind of disappointed about the outcome of what we thought we were doing right. I don't think that he was a perfect patient but I did what everyone was telling me was the right thing to do. I, you know, we made it part of our lives to walk, eat right you know. For years we did diet, exercise, low cholesterol. But doctors always have an excuse; they say lifestyle but look at our lifestyle! Don't smoke, hardly drinks. I never make a drink.

Focusing on the meaning of the present. The spousal caregivers were appropriately focused on the immediacy of their surgery but in the process, demonstrated a lack of focus of awareness around the chronicity of their spouses' underlying heart disease. The coronary artery bypass surgery was viewed as "fixing the problem". Not one of the spousal caregivers mentioned or alluded to the fact that the underlying coronary artery disease was an ongoing issue for their spouse. The spousal caregivers viewed the surgery

as a life-saving intervention that mitigated the underlying disease. Only one of the participants discussed the need to focus on other health issues of the recovering spouses. Olga, whose husband has lymphoma and melanoma, shared the following: “I think we are still in the midst of it. I almost feel like the heart stuff is all taken care of but now we have to focus on all the other health problems. We just have to keep plugging along.”

The spousal caregivers were often shocked about the diagnosis, alarmed with the elective scheduling of surgery and relieved when the surgery was over so they would be able to resume their presurgery lifestyles.

Jennifer noted her alarm at her husband’s diagnosis and the fear she had while waiting for his surgery.

Really, I didn’t feel safe about doing anything anymore. Even the littlest things seemed huge. And then, after he had the cardiac catheterization and they told us he had lots of blockages but then we could schedule it later....I couldn’t believe it. I thought they were going to bring him right in and do the operation. It was very frightening waiting to go to surgery and not knowing if he was every going to wake up in the morning. Or if we went for a walk, was he going to have an attack right then and there. So when the surgery was done, I was very relieved that nothing had happened. But I was scared to death to leave him alone or let him do anything. And oh boy, did he hate that. I did too.

Mary has a sense of relief when the surgery was over. She was extremely fearful of the possibility of her husband dying before they surgery could be performed.

You know I would wake up and think should we have done that yesterday, is today the day that he is going to have a heart attack? Do we go away, do we not go away? How far should I drive from home? I am more comfortable now that the operation is over.

Susan stated that she was grateful that her husband’s need for surgery happened early in their lives, but there is a sense of hesitancy and fear in accepting the chronicity of his disease and the changes that need to ensue. Susan’s husband has always taken

responsibility for his own health and Susan for hers. She is unable at this time to move beyond the surgical recovery and the impact that this experience has had on her, her husband and their children.

Seeing the Past Informing the Present. As participants engaged in the research process, a new understanding emerged for the spousal caregivers about their roles within their own families during their childhood and early adulthood years and how these experiences had informed the current caregiving experience. By giving the spousal caregivers the opportunity to reflect on their lives through dialogue and reflection on pattern, new realizations regarding the influence their life experiences had on their current experience began to emerge. With the recognition of pattern over their lifespan, the spousal caregivers began to have a new understanding of the meaning of their lives and for caring for their spouses after open heart surgery.

Many of the participants never had the opportunity to live independent of their parental or spousal relationships. Eight of the twelve spousal caregivers were married at twenty-two years of age or younger with most of the spousal caregivers living at home with their parents until they were married. Half of the spousal caregiver participants had a high school education or less. For some individuals, the transition from child/young adult to spouse also meant the transfer of dependence on parents to spouse. There was never an opportunity outside of the role of parenting for many of these participants so assume an independent role in life. The spousal caregivers and their spouses entered into a relationship at a young age and the evolution of the dyadic relationship between the spouse and the spousal caregiver produced a way of being, including roles and

responsibilities that have worked for them over the years. This caregiving experience presented new challenges for the spousal caregivers that required new responses and role changes that required reassessment and new direction.

Olga reflected on how during every significant event in her life, she had allowed only her husband to be involved: the birth of their only child, the care involved around their multiple illnesses, building their home together. She and her spouse made themselves available to others but refused help when offered to them. During the process of the interview, Olga came to recognize that she and her husband needed to give themselves permission to ask for help and to accept help. She stated:

Maybe it's time that I let someone help us. I could have killed my husband and me that day (referring to when she fell asleep while driving). Especially after all that we have just been through. I'm no spring chicken. Maybe I could at least get someone to help with the yard work so I can focus on my husband.

Madeleine had always depended on turning to her husband and away from major conflict or issues. She had escaped her childhood, one she considered marred by her mother's mental illness, by marrying at seventeen and starting her own family. She had chosen to focus on her husband and children when her father, mother and sister were ill. Now, in this time of crisis, Madeleine could not turn to her husband as he recovered from heart surgery and struggled with Alzheimer's disease. Madeleine's challenges were great. She had to face the uncertainty of her spouse's illness and accept that she needed to take control and confront a reality that is not always "okay".

During the interview process a theme emerged for several participants that focused on their moving away from the role of “baby” or being cared for to one that required taking control of their lives and their experiences. This was a new realization for these spousal caregivers. Three of the spousal caregivers, Katherine, Jennifer and Judy, were the youngest in their families and shared their reactions after recognizing this dimension of their life pattern.

Throughout her life, Judy’s always had someone caring for her. She was the youngest sibling and remained at home after her high school graduation until the time that she married. She lived in her hometown and remained close to her family. She had never needed to be the one to support others but had been the one supported. When she reflected upon this pattern it gave her motivation to support her husband during his recovery process and take control of his care and of her experience.

Katherine shared that she was the “slightly spoiled” youngest of five children. She was very close to her oldest sister who assumed care for Katherine and her other siblings. Katherine stated “So I was young and I never had to put up with, well not put up with any bad sort of stuff”. Katherine never had to confront or take control of any major issues in her life. She discussed how she was unable to have children but accepted it as the way life was supposed to be. With her current caregiving experience, she found the need to be more in control as she had more demands placed on her. When reflecting on her past, Katherine recognized the pattern that had emerged. She realized that this pattern would not work for her now and that she needed to accept responsibility and take new action. This awareness helped her move to a new level of consciousness.

Jennifer grew up in a warm, loving home with five siblings. She acknowledged that “I was the youngest and everyone took care of me.” The theme of being taken care of continued through Jennifer’s life. She married young, stayed at home with her children and was very dependent on her husband. After a family tragedy she reflects how her husband took control of her entire family during the crisis and beyond. She noted that her husband being in control “has always been okay for us” until this caregiving experience. When Jennifer reflected on her life pattern, she was able to discern that she has been dependent on the significant men in her life including her father, husband and son. Taking control during this caregiving experience has been difficult for her and she states

I guess this is what comes with growing up being the baby in the family. I find it very easy just to let someone else make the decisions; it is very hard for me to be the one in charge. I usually go along with what everyone else wants to do so this is a new experience for me.

Another manifestation of pattern across caregivers was the impact of a significant crisis or disruption in the spousal caregiver’s life and the reciprocal effect that this had on the spousal caregiver particularly related to “letting others take control” of situations. Bill’s life pattern from childhood on was one of expecting and accepting disappointments. Bill came to expect a worst case scenario no matter what the experience. These “worst case” expectations were based on his significant experiences in his earlier life including the loss of his father when he was five years old, the failure of his mother’s second marriage and the loss of his military career. Bill appeared to have lost any initiative to take control of the events in his life. His expectation of worst case was challenged when he realized he has lived longer than his father and that his wife was doing well after her open heart surgery. Reflecting on this pattern gave Bill the

opportunity to see that every situation may not end badly and that by taking control he may indeed have control over the events in his life. He realized that he could potentially influence how things unfolded.

Madeleine's childhood and early adulthood were informed by her mother's depression and the effect that this had on her father, Madeleine and her two sisters. By suppressing her emotions and distancing herself, Madeleine survived the pain. Immersing herself in parenthood and increasing the distance between her mother and herself, Madeleine was able to focus on her life and avoid the pain of her mother's mental illness. With this recent caregiving experience, Madeleine had to face increasing responsibilities and the potential of a future dominated by caring for her husband. Madeleine recognized her past coping mechanisms of suppressing her emotions and distancing herself allowed her to put on a "brave face", but restricted her interaction with life. Discussing her pattern offered Madeleine an opportunity for new action and change.

The overall impact of past caregiving experience on self. Many of the participants likened the spousal caregiving experience to mothering their own children. This was true for both the individuals who had cared for family members other than their children in the past and for those who had no caregiving experience outside of the parental role. Madeleine discussed the difficulty of the caregiving experience. "This is the hardest thing I have ever had to do in my life. It has just been going, going constantly. It is just like having children all over again." Jennifer was reluctant to tell her husband that taking care of him reminded her of being a mother.

You know what this has felt like, he wouldn't like this. But I feel like a new mother again. I don't want to leave him alone, I am watching everything he eats,

and I am keeping people away for a bit. I think being a mother was great preparation for this experience!

Many of the spousal caregivers had been peripherally involved in caring for someone in their family. There was a relationship between having a previous caregiving experience and the level of confidence and independence of the caregivers. Bill shared how one his siblings had been ill with lung cancer. He acknowledged that his other sibling had taken primary responsibility for caring for this ill sibling. Bill felt that the most he could do was visit his sibling and did not feel capable of caring for him. He shared this same emotion in regards to his wife after her surgery.

I don't think that I would be doing so good if I didn't have Kevin (his son) around or if things didn't go right. It goes by so quick. I know if there was something wrong she would tell me and I could get her to the hospital.

Katherine grew up with a sibling who was ill. She described it as “the emphysema”. She was not actively involved in her brother’s care, which she described as “quite demanding”. Although her husband required a nephrectomy for renal cell carcinoma, he is now cancer free and healthy. His postoperative recovery from that surgery had been uncomplicated and Katherine does not recall any major caregiving issues. She had never had responsibility for caring for an individual so vigilantly. With this caregiving experience, Katherine was at times overwhelmed in regards to the constancy of the care:

I kind of felt alone and you didn't have nobody to turn to like family. Knowing you didn't have anyone to turn to in case something came up. But it is kind of stressful and kind of depressing. But he was pretty good, he helped a lot, he helped me when I needed the help to help him.

Spousal caregivers who had experience with caring for a family member in the past, embraced this caregiving experience. For some it was an opportunity to show their spouses their love and dedication. Olga, discussed how her husband had cared for her in the past and now it was her turn to care for him. She stressed that she felt the need to give back to him and be independent in her caregiving.

I was very sick after the first aneurysm. I was sick for a year and a half. I walked like this (left foot turned in and dragging it as she walks) and um....

Nurse Researcher: Did you come home after your hospitalization or did you stay in a rehab facility?

Oh no, I came right home. I was pretty out of it for a year. Not really out of it, but I couldn't do anything. I just had horrible headaches. I came home early. And the day he brought me home, he washed his car and I helped him rinse it off.

Ruth, who had cared for both her mother, brother and her aunt in their later years, was convinced that no one else could care for her husband as well as she could. She had pushed for an early discharge from the hospital so she could assume the management of his care. When her spouse shared that he felt he had come home too early, Ruth stated:

Are you kidding? No!! Get him out of there the sooner the better so I could take care of him. I got him home and got him doing laps around the house. I tell him, "Get off the couch and get moving if you want to get better." We have been going out to lunch and everything. I don't think he has had that much pain either so let's get going. I mean he was sore but the more you move the better you will be. I was ready to take care of him and get him back to himself. I know I can be bossy, he knows that too. But, I do know what I am talking about and I know how to help people get better and he is.

Phase Two Summary

In answering the second study question, there emerged five themes from the data. These themes were clustered into five categories and included the following: 1) Disruption in caregivers' roles and responsibilities impacts relationships between the

spousal caregiver and spouse and shifts life patterns. 2) Spousal caregivers face coping challenges with changes in lifestyle and response to illness. 3) Spousal caregivers experience vigilance in an effort to ease the uncertainty of the recovery process. 4) Knowledge helps spousal caregivers gain a sense control in the face of uncertainty. 5) Mutual partnership between the nurse and the spousal caregiver in relationship impacts the potential for transformation. 6) Spousal caregivers' awareness of their life pattern gives meaning and offers the caregivers a new perception on life they have left to live. These themes brought forth an enhanced understanding of the spousal caregivers over their lifetimes and how these life experiences informed the spousal caregiving experience.

Chapter Summary

In this chapter, the meaning of the spousal caregiving experience as captured by pattern analysis was explained. Individual exemplars, comparison of pattern manifestations and themes across participants were examined. Six themes were identified in the process.

CHAPTER FIVE

DISCUSSION, IMPLICATIONS AND LIMITATIONS

The purpose of this study was to gain knowledge about life patterns, meaning and experiences of caregiving spouses of coronary artery bypass surgery patients recovering at home. In this chapter, the individual pattern of spouses as well as emerging themes across study participants will be discussed. Implications of the study findings for nursing education, practice, research, theory development and health care policy will be presented.

Margaret Newman's Theory of Health as Expanding Consciousness and Spousal Caregivers of Patients Recovering at Home following Cardiac Surgery

Findings from this study supported Newman's theory of Health as Expanding Consciousness. Research as praxis permitted the researcher and the spousal caregiver participants to share in the emergence of a new understanding about the caregiving experience of spouses after cardiac surgery.

Health as Expanding Consciousness

The current study reflected the use of Newman's praxis research method to examine expansion of consciousness in spousal caregivers. The process created an opportunity for new meaning and awareness of the caregiving experience in relation to self to emerge. Reflecting back upon the meaningful events and people in their lives gave the spousal caregivers a new perspective on and understanding of self and the caregiving role. The life pattern discerned by the nurse researcher in light of Newman's theory and then shared with the spousal caregivers was illuminating for these individuals

and gave the spousal caregivers an opportunity to reflect upon their caregiving experiences and their futures. Instead of viewing the caregiving experience as a crisis, the spousal caregivers were able to view the experience as a choice point in their lives that gave them the opportunity to gain new understanding and meaning that would inform the rest of their lives. In the process of being able to focus on themselves, their roles and relationships within a new understanding of self, the spousal caregivers experienced transformation.

Within Newman's Theory of Health as Expanding Consciousness, the nursing ideal is to be fully present with the client without judgments, goals or intervention strategies (Newman, 1999). Nursing intervention is a form of nonintervention. The presence of a nurse assists individuals with the recognition of their own pattern of interacting with the environment. In letting go of prediction and control, the nurse is able to concentrate on what is most meaningful to clients and the recognition of pattern.

With the recognition of pattern comes the potential for action and within that potential comes the possibility of transformation. It is important to understand that this recognition of potential for action occurs for both the nurse and client and should not be seen as a means to an end, but rather as its own reward (Newman, 2007). The transformation that occurs with this insight and new awareness is nurtured by the mutuality within the nurse-client relationship. In the current study, there was recognition of the potential for action by the study participants and the nurse researcher. The time spent with the study participants did not permit the nurse researcher to see the actualization of that potential. This speaks to the need to follow study participants over an

extended period of time in order to have a true understanding of the impact of transformation.

The mutuality present within the nurse-client relationship in the context of Health as Expanding Consciousness permits nurses to fulfill what is considered the responsibility of nursing "... not to make people well, or to prevent their getting sick, but to assist people to recognize the power that is within them to move to higher levels of consciousness" (Newman, 1999, p. x). Central to this nurse-client relationship is the need to honor what is meaningful to the client. Newman (2007) discusses that a nurse must dismiss preconceived notions and focus on being fully present in the moment. It is within the context of this intentional presence that a transformative relationship may develop with the client. If the essence of a human being is relationship (Newman, 2007) then focus within the nurse-client relationship should be on connection between the nurse and client, not on prescriptive practice.

This study demonstrated how a meaningful, mutual partnership between the nurse researcher and the spousal caregiver became transformational for both individuals (Newman, 2008). Within the mutual relationship, the nurse-researcher was able to grasp the pattern of the spousal caregiver as a whole. In the process, the nurse researcher was able to gain new understanding of the following: the spousal caregiving experience and the importance of nursing presence across the experience, the significance of truly knowing the patient and the patient's significant others, and the value of the research as praxis in daily practice.

Within the mutual relationship with the nurse researcher, spousal caregivers demonstrated varying levels of expansion of consciousness. These individuals were given the opportunity to focus on those meaningful events and people in their lives and in the process gained a new understanding of themselves, their relationships with significant others and the impact of their life events on the present and the future. The interactive, guiding relationship between nurse researcher and spousal caregivers was mutually rewarding and contributed towards emotional growth. By making the shift from “onlooker” to participant, the nurse researcher allowed herself to become the means through which the spousal caregivers could potentially achieve an expanded level of consciousness (Newman, 2007).

An interrelatedness emerged with each participant pattern analysis and across participants that supported the connection between movement, boundaries, time and space as described by Newman et al (2004). For many of these spousal caregivers, this caregiving experience was one of the first times in years that required them to emerge out of their dyadic relationship with their spouse and make the decision to act independent of their spouse. Because of the uncertainty these caregivers shared in regards to their spouses’ course of recovery including symptoms of depression and the vigilance that they expressed about taking care of their spouse, these caregivers began to recognize that existing coping strategies were ineffective.

This recognition began a movement towards a new definition of self as individual and self as part of a relationship. In the process, new boundaries were formed between the spousal caregiver and spouse, children, friends and other family members. Newman

(2003) discusses how it is essential to help individuals recognize and let go of artificial boundaries that have been established in their lives. By letting go, an individual permits the inner voice or the implicate pattern to unfold (Picard & Jones, 2005). This process allows an individual to reach out and explore new relationships and experiences. For these spousal caregivers, recognition of the implicate pattern was recognition of the artificial boundaries that had been created in their lives. By dismantling these boundaries, these individuals could begin the movement towards transformation and transition.

The diminished social and altered personal spaces as well as the loss of personal space and time conveyed by the spousal caregivers were closely correlated with their focus on the immediate caregiving experience and the restrictions they placed on themselves or felt were imposed upon them. The vigilant behavior of the spousal caregivers could be seen as a manifestation of their concern for their spouses and the uncertainty the spousal caregivers felt regarding the recovery process. The spousal caregivers' altered perception of personal space and diminished ability to move within established social spaces affected their ability to use pre-existing coping mechanisms. Altered personal and social space could also be viewed as contributing factors towards the themes that emerged involving physical exhaustion and emotional constraint.

The expression of both physical exhaustion and emotional constraint may be explicate manifestations of a perception of loss of personal time and the struggle to begin movement towards a new understanding of the caregiving experience and the new roles and responsibilities that come with it. Newman describes individuals as bound in time and space (Newman, 1999). The participant's outward struggle to incorporate the

challenges and role changes associated with the caregiving experience may be viewed as blocked energy flow. This blocked energy flow could be a contributing factor to the explicate manifestation of physical exhaustion described by the study participants.

The most compelling themes in regards to Newman's theory emerged in relation to the spousal caregivers' realization of their pasts informing their present and future. These themes in particular resonated with Newman's theory and manifested how praxis (Newman, 1999) gave the spousal caregivers the opportunity to reflect on the meaningful events and people in their lives. In the process of reflecting upon their lives, the spousal caregivers were able gain an understanding and insight about how perceptions of pattern were intricately linked. Even those spousal caregivers who were struggling to move beyond the immediate effects of the caregiving experience were able to come to a new awareness of the events and meanings of the relationships in their lives with the opportunity for guided reflection. These themes correlated with Newman's concepts of time, movement, boundarylessness; concepts that are all necessary components for the realization of the possibility of transformation.

The influence of childhood events and family roles on adulthood as defined by the spousal caregivers, the awareness of present reality, and the capacity for transformation were present in nearly all of the spousal caregivers' pattern analyses. Early childhood trauma and chaos including loss of a parental figure due to illness or death, loss of a sibling, remarriage of a parent and subsequent step-siblings all had an influence on the spousal caregivers' perception of self as part of a dyad, a parent and as an individual. Another significant finding was the influence of family order on the

spousal caregiver's perception of present day roles, responsibilities and individuality.

Spousal caregivers who were the youngest siblings in their families appeared to maintain certain aspects of being the "baby of the family". This was particularly evident in the areas of being supported by others, allowing others to make decisions, and in attempting to recreate their own childhood for their children.

Newman (1999) describes an individual's binding in time and space as influenced by the physical self developed in childhood. This childhood self provides a sense of self in relation to the present environment. Chaotic experience like the ones described from this current study may continue to impact an individual's life and ability to recognize the potential for change. The findings regarding early childhood chaos are similar to the findings described by Noveletsky-Rosenthal (1996), Pharris (2002) and Rosa (2006).

For the spousal caregivers, recognizing patterns began the process of gaining a new understanding of self and of the meanings behind their actions in their present lives. This awareness occurred as the spousal caregivers realized the influence of their past on their present and future; the movement toward potential transformation that comes with this recognition; and, the need to release the boundaries they have placed upon themselves in their lives.

Health as Expanding Consciousness and Young's Stages of Human Evolution

Within this study, spousal caregivers' reflections and recognition of their potential ability to move forward within the caregiving experience and beyond presented the researcher the opportunity to realize the importance of the interrelationship between Newman's theory (Newman, 1994) and Young's stages of human evolution (Young,

1976). For both the researcher and the study participants, there was the individual's recognition of pattern, a desire to move forward and the potential for human evolution and transformation.

Following the research protocol (Chapter Three), the twelve spousal caregivers recruited for this study were each placed at the appropriate stage of Young's Stages of Evolution (Young, 1976). The life pattern of spousal caregivers placed at 'Binding' and 'Binding/Centering' revealed a resistance to change and the perception of the need for control. Within Young's theory, 'Binding' is denoted by conformity and control and 'Centering' is marked by a sense of self (Young, 1976). The life pattern analyses for these two participants revealed important issues with authority and control. The pattern for the spousal caregiver placed at Binding carried the theme "Allowing others to Control". The spousal caregiver placed at Binding/Centering revealed the pattern of "Caring for Others in Order to Care about Self".

There were four participants placed at the 'Choice' stage. This stage is defined as recognition that old ways no longer work (Young, 1976). Spousal caregivers at this stage recognized the impact of the caregiving experience, were deeply involved in their spouses' care and were just beginning to recognize the implications of this caregiving experience on the rest of their lives. These participants were beginning to acknowledge the potential for choice in their lives. These choices were informed by the recognition of and reflection on their life pattern. The participants at this stage were the spousal caregivers who described feeling empowered by the research process. They were given the opportunity to discuss new choices as ones that could be informed by their past

experience. The themes that emerged for these individuals included “Allowing Others In”; “Acceptance as Action”, “Avoiding Action and Expecting the Worst Case Scenario” and “Being Cared for through Life”.

The six participants placed at the ‘Decentering’ stage had at some point during the caregiving experience and the research process begun to experience transformation.

‘Decentering’ is defined by Young (1976) as a period of inner growth or transcendence. The interview process and the result unfolding life pattern analyses were reinforcing and informative to these spousal caregivers and provided an opportunity to make meaning of their current situation and need for change. These participants expressed openness to change and were in the process of gaining new understanding about themselves and their lives. They were beginning to seek new actions to assist them with life changes and looking for ways to sustain these changes. The themes that emerged for these individuals included “Putting on a Brave Face”, “Supported through Life’s Crises”; “Living the Perfect Life”; “Protecting from the Potential Pain”; “Fear of Uncertainty” and “Always the Supported not the Supporter”.

Understanding an individual’s capacity for transformation and expansion of consciousness is critical in the formation and implementation of effective actions. Responses on the caregiving experience enabled participants to address unmet personal needs, enhanced ability to accept potential change and direction needed to promote growth in the human experience. Using Newman’s theory of Health as Expanding Consciousness in combination with Young’s Stages of Evolution (Newman, 1999) to gain an understanding of where an individual is in the process of expansion of

consciousness may help researchers gain an improved understanding of an individual's readiness for change and the receptivity to action.

Expanding upon Health as Expanding Consciousness

There is potential for expansion of Newman's theory and research method. Newman's research methodology could be expanded upon by extending the number of encounters with clients across time. Newman (2007) discusses the movement of the nurse-client during transformation as rhythmic. The nurse and client come together as One in pattern recognition and then move apart as transformation occurs. Newman does recommend a minimum of three meetings with a client to reflect on new insights for both the nurse and client. However, extended interactions with clients beyond the initial three meetings may capture the process individuals experience as they transition from acute to chronic illness, the effects of long-term recovery, the ongoing impact of transformation on lives over time and the effect of how expansion of consciousness is sustained during future crises and chaos.

Conclusion: Health as Expanding Consciousness

In conclusion, using Newman's Theory of Health as Expanding Consciousness offered a new way to gain understanding of the spousal caregiving experience of patients recovering at home following cardiac surgery.

Nursing praxis is a dialogue of an evolving pattern of meaning, insight and action and is transforming for both the nurse and the client (Newman, 2007). The findings from this study related to meaning, pattern and expansion of consciousness supported the theoretical assumptions of Health as Expanded Consciousness and nursing praxis. There

is a need to examine the possibility of extending Newman's research methodology over a longer time frame in an effort to fully understand the impact and long-term impact of personal transformation. This may expand upon Newman's theory and offer further validation of the research method.

Linkages to Selected Theories and to Extant Research

The study findings from this research can be viewed in relation to other theories and existing studies focusing on disruption of role and responsibility related to the caregiving experience, the need for knowledge related to the uncertainty of the recovery trajectory, mutuality within the nurse-patient relationship and the impact of an individual's life experiences on the caregiving experience and beyond.

Disruption in Caregivers' Roles and Responsibilities Impacts Relationships between the Spousal Caregiver and Spouse and Shifts Life Patterns

In his studies focusing on family assessment, problem solving and adjustment to crises, Hill (1970) delineated a process by which families define a crisis. He identified four interrelated but conceptually distinct factors which influence a family's ability to cope with the illness experience: the characteristics of an event; perceived threat to family relationships, status and goals; resources available to the family; and past experience with the same or similar situation. Hill stated that role prescriptions of family members specify appropriate behaviors and regulate the relationship of members daily and overtime. When a crisis, like illness, is present individuals do not abdicate their roles. The role impairment or disruption that may be experienced by family members during a crisis is dependent on the severity and length of illness; the ability of the family members

to modify their respective roles; the capacity to perform tasks essential for the continuity of family life, and a redefinition of personal expectations and goals. Hill stated that when there is a crisis there needs to be a reorganization of the family to achieve a new equilibrium.

Archbold (1976) expanded on Hill's theory in her work with family caregivers. In order to understand a family's capacity to cope with illness or a crisis event, Archbold stated that it is necessary to understand the patient's knowledge and perception of his or her condition; the knowledge, perception and response of significant others to the illness; perceived threat to family relationships, status and goals; available resources to the family caregiver and past experience with crisis situations. Past experience with crisis was viewed as a strong determinant of family decision-making and as a variable that gives insight into the basic patterns of coping behavior already in the family's repertoire.

In the work on mutuality and preparedness of caregivers, Archbold (1990) elaborated caregiving as a role. This study discussed how caregivers learned aspects of the caregiving role and how they evaluated their ability to conduct the role. Mutuality and preparedness were associated with lower levels of caregiver role strain but not all aspects of strain. Specifically, higher mutuality and preparedness of the caregiver produced the following: Less strain from direct care; less tension less global strain; no effect on economic burden, worry, role conflict; and limited effect on strain due to lack of resources. Archbold found that a positive relationship between caregivers and care recipient produced less strain because the caregivers found the caregiving inherently meaningful.

Most of the spousal caregivers in this study experienced high levels of mutuality and the caregiving experience was viewed as meaningful. However, the level of preparedness was not perceived as adequate for the study participants based on their stories. There also seemed to be a point where the mutuality was so high in the dyadic relationship that difficulties arose when the spousal caregiver chose to act outside of pre-established dyadic roles. This immersion of self into the dyad presented barriers to asking for assistance, challenges to communication between the spousal caregiver and the recovering spouse and for some a distrust of those outside of the dyad when it came to the caregiving experience.

Shyu's (2000) study focused on the interactions between the caregiver-care recipient dyad during the immediate transition to home from the hospital. The investigator described a three phase transitional process, defined as 'role tuning', used by the dyad to achieve a harmonious pattern of caregiving and care receiving after leaving the hospital. The concept of 'role tuning' emphasized the interactive nature of the caregiver and care recipient roles. In order to cope effectively with the role changes inherent to the caregiving experience, Shyu's research suggested that both the caregivers and care recipients needed to learn their new roles and then adjust their behaviors according to each others' response to the change in role. Individuals who developed issues with the role tuning process included those with inadequate resources, high levels of uncertainty in the illness trajectory, sudden onset of severe illness and a significant role or life change for the caregivers. Role tuning was still in effect for some of the spousal caregivers in this study. Study participants did have characteristics identified by

Shyu that could create challenges in the role tuning process namely, high levels of uncertainty in the illness trajectory, and a significant role or life change for the caregivers.

Coeling's (2003) research focused on the ways in which caregivers and their care receivers negotiate dyadic rules that influence how the care experience fits into their lives. The study findings indicated that a mutually agreed-upon dyadic identity is developed when both parties negotiate a set of rules about their conduct together in the caregiving and care receiving relationship. If these individuals failed to agree on these dyadic rules there was strain in the caregiving process. Coeling identified three types of dyadic relationships based on the degree of immersion into a dyadic identity including: 1) complete and mutually accepted immersion of an identity into the care process by both parties; 2) retention of personal identities while also accepting the caregiving or care-receiving roles; and 3) rejection of the roles by one or both parties. He concluded that it is essential that nursing assist caregivers and care receivers in developing negotiation skills necessary to be successful in the caregiving process. The findings from this investigation suggested varying levels of immersion into the caregiving dyad. This concept has a critical effect on the perception of success in caregiving and on the creation of individualized interventions.

For the participants in this study, the immersion of self in other began before the caregiving experience. The challenges associated with the caregiving experience provided an opportunity for some of the spousal caregivers to either consciously or unconsciously move from a level of dyadic immersion of "me into we" to "me and we".

This change in the level of dyadic immersion in the presence of crises such as illness requires further investigation. There needs to be further inquiry into effect on the individuals and their relationships when a pattern of being dependent on another suddenly changes. This inquiry calls for earlier interaction with the caregiving dyad, preferably before the disruption of pattern associated with the caregiving experience, preservation of dyad through crisis and inquiry regarding the reunion of the dyad at a higher level of consciousness.

Spousal caregivers face coping challenges with changes in lifestyle and response to illness

The extant literature about spousal caregiving and coping focuses primarily on individuals living with dementia, chronic illness and end of life care. There is little to no research regarding the challenges that caregivers face from coping with the changes in lifestyle and response to illness after their spouses' cardiac surgery.

O'Farrell et al (2000) discussed the correlation between distress and the use of disengagement coping strategies among spouses of patients undergoing cardiac rehabilitation. Distress was described by the spousal caregivers as feeling tense, having trouble falling asleep and feeling easily hurt. The most frequent stressors noted by the spousal caregivers were worries about treatment, recovery, and prognosis; moodiness of the patient; worries about the patient returning to work and about money; sexual concerns; helplessness or apathy on the part of the patient and increased spousal responsibility. O'Farrell concluded that spousal caregivers should be screened for

psychological distress and offered stress-management techniques and support but did not elaborate on the need for new coping strategies.

Mahrer-Imhof, Hoffman & Froelicher (2007) interviewed 24 spousal dyads after one of them had been admitted to the hospital following an acute cardiac event and had also participated in cardiac rehabilitation. In this phenomenological study, three in-depth interviews were obtained for each dyad: one couple interview and two individual interviews with each partner of the dyad. All couples described experiencing the feeling of a 'brush with death' with the diagnosis of heart disease and recognized the diagnosis as the need to begin changes in lifestyle.

Three distinct patterns of dealing with the cardiac illness emerged for the spousal dyad from the study findings. The first pattern revealed couples who assessed the illness as a positive, transformative experience in their lives and experienced a closer relationship. The second pattern showed couples who experienced the illness as a threat and although fearful, worked collaboratively on lifestyle changes. The third pattern revealed couples who experience a missed opportunity to change. These couples had a period of disenchantment but were reported to return to life as usual. As with the O'Farrell study, there was an acknowledgement of lifestyle change but no discussion on how this affected pre-existing coping strategies.

The findings from the current study regarding issues around ineffective coping included altered perception of personal space and time, the need to adapt pre-existing routines to accommodate caregiving, physical exhaustion and emotional constraint associated with caregiving and the search for new ways of coping. The spousal caregivers

recognized the need for new behaviors in order to cope with the challenges of the caregiving experience. Through pattern recognition, the spousal caregivers gained a new awareness that coping strategies that had been used in the past were now ineffective. This may be an illustration of expansion of consciousness and the recognition of potential for action.

Seeking new behaviors in order to cope with the caregiving experience may also be a reflection of the recognition that there is no “return to life as usual” as described by Mahrer-Imhof et al (2007). For those immersed in the theory of Health as Expanding Consciousness, reality is the present (Newman, 2007). During times of chaos, like the spousal caregiving experience, an individual chooses to either remain at his or her existing consciousness or to recognize the meaning within the chaos and expand his or consciousness. The recognition of what was in the midst of chaos leads to recognition of the potential for action and change.

Spousal Caregivers Experience Vigilance in an Effort to Ease the Uncertainty of the Recovery Process

Vigilance in family caregiving is documented in the literature in regards to family caregivers of individuals with Alzheimer’s disease (Belle et al, 2004; Mahoney, 2003; Zanetti et al 1998). Although there is a vast amount of literature regarding the uncertainty of the recovery process in the postoperative cardiac surgery patient, only one study discusses spousal caregiver vigilance.

In her study regarding the experiences of being a caregiver of a cardiac surgery patient during the immediate post discharge period, Knoll (2000) found that the

caregiving experience was molded by caregivers' past participation as a caregiver, as well as caregivers' and care recipients' outlook on life, their interpersonal relationship, and their expectations. Caregiving involved processes that included vigilant behavior, implementing strategies to assist the recovery process, and taking on a role to provide care and seek help as required. The caregivers experienced feelings of stress, vulnerability, and having to put their lives on hold; these feelings were often compounded by uncertainty. The variables that Knoll (2000) discussed as foundation to the caregiving experience are also present in this study. Knoll's study focused more on the feelings that family caregivers experienced during the study and the uncertainty that emerged.

In the current study, nearly all of the spousal caregivers described a sense of vigilance when it came to caring for their spouses. The spousal caregivers were fearful of leaving their spouses alone and monitored their spouses closely for adherence to restrictions, medications and physical issues related to recovery. They also felt challenged by their spouses who at the time thought them to be too overprotective and hovering.

Knowledge Helps Spousal Caregivers Gain a Sense Control In The Face Of Uncertainty

The findings of this study suggested that spousal caregivers felt ill prepared to deal with the uncertainty of their spouses' recovery from surgery at home. The spousal caregivers appeared to believe that having the caregiving experience go well was equal to their following discharge directions well. What was lacking for these participants in this investigation was knowledge about recovery variability during the first weeks at home

and the emotional impact this variability had on both the caregivers and the recovering spouses.

In studies focusing on family and spousal caregivers, the need for knowledge in the face of the uncertainty of the recovery process after cardiac surgery is supported. Most of these studies describe the patient and his/her perceptions. A study by Davies (2000), however, focused on spousal caregivers for the postoperative coronary artery bypass patient. In Davies' study spousal caregivers expressed the feeling that their personal needs remained unmet. These unmet needs included the lack of information regarding what is typical or not in the weeks following surgery, how to manage the pain and the fatigue of a postoperative patient, and the unexpected overwhelming responsibility that is incurred with caregiving process. All of these unmet needs fostered increased anxiety and uncertainty as these individuals assume the role of caregiver. Davies' study findings are consistent with the findings from this study. The need for ongoing links between provider and caregivers around response to illness is essential

Theobald (2004) interviewed individuals who were post CABG surgery and their family caregivers three months and one year after discharge to home. All of the participants in the study recommended strengthening discharge planning with more accurate information about what to expect during recovery, to help both the patient and the caregivers anticipate fluctuations in health and wellbeing. Caregivers experienced a wide range of unanticipated feelings during early recovery and had to deal with a number of personal changes. These findings are also consistent with the knowledge deficit and feelings on uncertainty findings from the current study.

Davies' (2000) also reported the findings from a descriptive survey of 59 caregivers of cardiac surgery patients. Data were obtained by questionnaire during one week following discharge and then six weeks later. The questionnaire focused on caregivers' perceptions about the timing of discharge from hospital, opinions of the information provided by hospital staff, and anxiety and depression measured on the Hospital Anxiety and Depression Scale. Study results included the following: caregivers felt they assumed a heavy burden with the caregiving role; they were less satisfied with the timing of discharge at one week after discharge than those questioned at six weeks, and information provided by nurses was rated more highly than that provided by doctors or therapists. The findings from Davies' study also suggested that cardiac discharge education needs to be aimed at caregivers as well as patients and that targeted caregiver support could facilitate patient recovery and rehabilitation.

In the current investigation, spousal caregivers were concerned about the uncertainty they feel with the variability of their spouses' recovery. Mishel (1988) defines uncertainty as "the inability to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues" (p. 225). Uncertainty within the situational experience of illness is measured with four key factors: ambiguity concerning the state of the illness, complexity regarding treatment and the system of care, deficient information about the diagnosis and seriousness of the illness, and unpredictability regarding the course of the disease and prognosis (Mishel, 1997.) Mishel also considered uncertainty as separate from its emotional outcomes. Mishel's Uncertainty in Illness-

Community Scale has been used to examine the trajectory of uncertainty and psychologic stress for recovering patients during the first three months after coronary angioplasty and coronary bypass surgery (White & Frasure-Smith, 1995).

The uncertainty that the spousal caregivers discussed in this study reflected the key factors outlined by Mishel, ambiguity, complexity, deficient information and unpredictability. The striking difference is that their uncertainty was intricately linked with emotional outcomes related to themselves and their spouses. The labile emotional state that some of the spouses demonstrated was a contributing factor to the spousal caregivers' uncertainty. Some of the uncertainty demonstrated by the spousal caregivers emerged from not knowing how their spouses would react to being told what to do or not to do, how their spouses' would feel each day, and the variability of depression that some of the spouses experienced. These components were influenced by fatigue, loss of energy and altered perception of time and space.

The spousal caregivers in this study discussed fatigue associated with the physical demands of caregiving. However, of greater concern to the caregivers was their ability to do the caregiving well. The uncertainty they felt and a lack of knowledge on how to manage unexpected daily challenges was physically and emotionally wearing. An important variable in the spousal caregivers' perception of doing caregiving well was the perception that their spouses also believed that the caregiving was done well.

Schumacher's (1998) work with family caregivers demonstrates the vital importance of caregivers' perceptions of doing caregiving well. She discusses five concepts that are related to doing family caregiving well: caregiving mastery, self-efficacy, competence,

preparedness and quality of the caregiving. What is not discussed was the care recipients' perception of care received, a variable that was demonstrated to be important to the spousal caregivers in my study.

The findings from this current study indicated the need for focus during discharge education on the variability of the recovery process, the potential for the recovering spouse to experience depression and the impact both these variables have on the caregiving process. Archbold (1990) recommended that nurses should include in their discharge assessment the quality of the family caregiver's relationship to the care recipient and that nursing interventions designed to improve the caregiver preparedness need to be applied when they are salient, following the care recipient hospitalization. There is limited evidence in the existing literature to support caregiver's capacity to translate provider recommendations into the real life. This limited evidence supports the need for a continued relationship with nursing after transition to home and interventions focusing on caregivers' perception of uncertainty within the caregiving process.

Findings from a study focused on unpartnered elders recovering from cardiac surgery (Rankin, Butzlaff, Carroll & Reedy, 2005) indicated that functional and emotional support from a clinical nurse specialist over an average 14 week period after discharge to home from the hospital enhanced self efficacy for recovery from cardiac events. Nursing presence across time may assist caregivers with the transitions that they face throughout the caregiving experience.

*Mutuality within the Partnership of the Nurse and the Spousal Caregiver Relationship
Impacts the Potential for Transformation*

There is an appreciable amount of literature regarding knowing the patient. Radwin's (1995) work defined knowing the patient as a purposeful action whereby the nurse uses understanding of the patient's experiences, behaviors, feelings, and/or perceptions to select individualized interventions. Tanner (1993) viewed knowing the patient as both knowing the patient's typical pattern of responses and knowing the patient as a person. Whittemore (2000) stated that knowing the patient encompasses the complex process whereby the nurse acquires understanding of a specific patient as a unique individual, which subsequently enhances clinical decision-making, selection of optimal nursing interventions, and patient outcomes. Lauver (2002) defined knowing the patient as "Purposeful action by nurses to seek to understand the patient's experiences, behaviors, feelings and perceptions" (p.247).

All of these definitions associated with "knowing the patient" take the experience beyond the disease or the crisis. Part of the mutuality process involves the feeling of being known. This is true for the nurse and the patient, client, family. In the process of opening oneself to being known, there has to be a sense of trust, comfort for the involved parties. Within the trusting relationship, a new understanding of self and other evolves. This mutual collaboration needs to be incorporated into the concept of knowing the patient.

Endo (2005), in a study focused on incorporating Health as Expanding Consciousness into nursing practice, discussed how at the beginning of the process of

integrating Newman's theory into daily practice, nurses remained focused on curing, not engaging with the patient. As the nurses began to engage in a caring relationship of pattern recognition with clients, they began to experience the patients' transformations in a way that was also transformative for them. This experience of mutuality and transformation changed the way they approached the nurse patient relationship and the way they practiced nursing. "The mission of nursing is to help clients find meaning in the evolving process" (Newman, 2007, p.52). In order to attend to this mission, nurses need to be fully present in the process. This was indeed true for this nurse researcher during the course of this study.

*Spousal Caregivers' Awareness of Their Life Pattern Gives Meaning And Offers The
Caregivers A New Perception On Life They Have Left To Live*

At the time of this study, there are no other published research studies that have used Newman's Health as Expanding Consciousness to explore the experience of spousal caregivers of coronary artery bypass patients. Newman's theory and research method have however been used in several other research studies associated with chronic health problems. These studies include the following: focus on life meaning and cancer (Barron, 2000); women maintaining weight loss (Berry, 2004); Japanese women with ovarian cancer (Endo, 1998); expanding consciousness in midlife women (Picard, 2000); living with chronic skin wounds (Rosa, 2006); older adults living with chronic illness (Noveletsky-Rosenthal, 1996); and pattern recognition of incarcerated mothers (Hayes, 2007).

Studies that have used Newman's Theory with family caregivers have demonstrated transformative experiences for study participants. The first study pertaining to family caregiving was Endo's (2000) study focusing on Japanese family caregivers of wives-mothers hospitalized with a cancer diagnosis. There were a total of ten families in the study, with four nurse-researchers interacting with each of the different families. The participants included the women who carried a cancer diagnosis and the primary family caregiver. Each participant was asked to describe the meaningful persons and events in their family history. In the process of the research, most of the families found meaning in their pattern. The families experienced increasing openness, connectedness and trustfulness in caring relationships and shifted from separated individuals within the family to trustful caring relationships.

A second study conducted by Yamashita (1999) involved twelve family caregivers of individuals suffering with schizophrenia. Through the process of pattern recognition, these family caregivers came to see new meaning in their relationship with their family member who was diagnosed with schizophrenia and a new understanding of the challenges they faced. The family caregivers expressed that they came to see the caregiving experience not as a burden but as an opportunity for transformation. This remained true regardless of the length of their family member's illness. Through expansion of consciousness, the caregivers shared they felt a deeper connection and relationship to their family member and that they were able to separate their family member from behaviors inherent to the schizophrenia diagnosis.

In both Endo and Yamashita's studies, there was a movement towards new understanding regarding meaning within family relationships, how the family caregiver perceived other (wife-mother with cancer or family member with schizophrenia), and recognition of a new understanding and acceptance of their relative's health issues. The difference between these two studies and this study regarding spousal caregivers of coronary artery bypass surgeries is the focus of the movement the individual, not the family towards expansion of consciousness.

In addition, the spousal caregivers were able to re-examine their own health issues within the process, recognize their own mortality, realize of the quality of life left to live and experience how their spouses' perceptions were similar or different from their own. This was informative for the spousal caregivers who participated in this study and emerged through reflection and collaboration with the nurse researcher.

Implications

Nursing Theory Development

There is a gap in the literature of theoretically-driven research regarding the spousal caregiving experience. If nursing is to continue in its efforts to develop and sustain its unique body of knowledge, then it is critical that nursing research be theory driven. It is through the integration of theory, research and practice that meaningful theories will emerge (Meleis, 1998). "Nursing theory expresses the values and believes of the discipline, helps to frame the human experience and guides the caring process" (Roy & Jones, 2007, p. 28).

The difficulty experienced by nursing at times in describing its unique body of knowledge may be due to the fact that the knowledge that keeps the patient central to the discipline of nursing may be knowledge that cannot be represented and or recognized by those outside of the discipline. That is why it is critical for nurse researchers to continue to provide direction for theory building, substantive area development and commitment to nursing's methodological philosophy and clinical research (Roy, 1999). Theory is iterative, dynamic and evolving. The very nature of theoretical knowledge development calls for clarification of existing knowledge and discovering of new innovative content that both informs and guides research and practice (Roy & Jones, 2007).

This is the first research study to use Newman's theory and research method in regards to spousal caregivers and the postoperative coronary artery bypass surgery patient recovering at home. By focusing on the meaningful people and events in an individual's life, the researcher was able to gain a deeper understanding of meaning in the spousal caregiving experience. The theory-driven focus on the effects of meaning for these individuals and their potential for expansion of consciousness and transformation has potential to guide research which in turn may inform nursing practice about new outcomes and potential interventions for the caregiving population and how the mutual process in praxis links knowledge with care.

Nursing Research

It is critical to recognize the significance of research that is grounded within a nursing framework. Studying a phenomenon from a nursing perspective produces knowledge that is foundational in the creation of effective nursing interventions. These

nursing interventions are ones that can be used to improve health care delivery and gain understanding of an individual's health experience. With an improved understanding of the meaning within an individual's life pattern, nursing has the opportunity to have an improved understanding of what support these individuals' needs within new experiences.

Newman's research method provides individuals with the opportunity to know themselves, to find meaning in their current situation and to gain insight. For many individuals, this is an intervention in of itself. Further inquiry into exploring pattern recognition as a nursing intervention could provide crucial information regarding how an individual evolves through the process of expanding consciousness. Using the stages of evolution within Young's Spectrum to gain understanding of where an individual is in the process may provide information that would allow nurses to facilitate the evolution of consciousness.

Newman's Health as Expanding Consciousness provides a research method that permits the nurse researcher gain an understanding the pattern of the whole. With this new understanding, there is potential to create nursing actions that are individualized and supportive of continued growth. Research based with Newman's theory has great promise to promote and support the theory-research-practice link that is so critical to knowledge development and ultimately patient care.

Nursing Practice

A significant finding that evolved from this study was the need for a redesigned environment of care for nursing practice. This new environment of care must be one that

allows nurses to develop relationships and have sustained interactions with their patients and patients' significant others across time and space. Nurses need to be able to assure the health of not only the individual patient but also of those individuals within that patient's life who are essential to the caregiving process. In order to achieve this goal, nursing must have the power to expand beyond the current environment of care and be able to acknowledge and meet their patients' needs in a mutual, reciprocal partnership geared toward transformation and expansion of consciousness.

One way that the continued presence of nursing may be assured is establishing relationships with patients and caregivers earlier in the hospitalization process. Meeting with caregivers prior to surgery and offering the opportunity for reflection before the caregiving experience begins may provide important information about individual caregiving experiences. . The caregivers' meaningful reflections could be used to assist both the caregiver and the nurse in the discovery of new meaning during the caregiving experience. Discovering what is meaningful to patients and caregivers before surgery could also promote an environment in the postoperative time frame that is more conducive to transformation for the nurse, the patient and the caregiver.

In her work with developing the Preadmission Nursing Practice Model based on Health as Expanding Consciousness, Flanagan (2005) transformed an existing nursing practice model from a disease focus to a process focus with an emphasis on nurses knowing their patients and what is meaningful to their patients. The nurses involved in the study shared their joy with being able to focus on the patients and experience an authentic presence with them. Flanagan emphasized that the creation of a model of care

grounded in a nursing practice model requires vision, nursing leadership, commitment and mentoring.

Ruka (2004) incorporated Health as Expanding Consciousness pattern recognition into the model of care at a long-term care nursing facility. She found that when pattern analysis was used to exam behavior, patients and staff change and relationships are transformed. Ongoing dialogue between all levels of staff led to the development of openness and connectedness among team members. This mutuality was then easily extended to the residents and their families. The process of incorporating HEC into the model of care was also a process of uncertainty and transition. However, because of the increased comfort of the staff and trust in each other the process of a new care environment continued to transition.

Lastly, the inquiry may be simple, but the implications have great potential: Are nurses asking the right questions about the caregiving experience? Are the discharge education programs in place meeting the needs of spousal caregivers? If nurses do not have the opportunity to discover what is meaningful to individuals, how can nurses direct appropriate questions to discover meaning and unmet needs of caregivers? Nurses need to re-evaluate discharge education for caregivers. The focus of this education needs to be less skill and task driven and more inclusive of the potential emotional ramifications of assuming the caregiver role.

Nursing Education

This study demonstrated the importance of incorporating the Unitary Transformative Paradigm into nursing curricula at all levels of preparation. Newman

believes that “the nature of nursing is a dynamic, relational process, and to understand it we must engage in the experience of it” (Newman, 1997, p. 36). She calls for a shift from the treatment of symptoms to searching for patterns; a reexamination of disease and disruption that eliminates the negativity associated with these concepts and redefines them as essential parts of the self-organizing process of the expanding consciousness; and, a shift in the definition of the nursing role from one that addresses the problems of disease to assisting individuals get in touch with their own pattern of expanding consciousness (Newman, 1999).

This shift that Newman speaks of must begin at the baccalaureate level and be nurtured through doctoral preparation. There must be a shift away from educating young nurses on the categorization of individuals by pathology and medical interventions to the recognition of individual’s responses to human health experience and the meaning the experience carries. There must also be a shift away from the mentality of nursing as a prescriptive process to nursing as a collaborative, intentional, caring relationship with patient or client; a relationship that uncovers meaning and potential for growth.

Newman states “attention to the nature of transformative learning experiences will help establish the priorities of the discipline” (Newman, 2007, p. 73). . Within the Unitary Transformative paradigm, students are educated to experience the art of reflection and the importance of meaning. Reflection allows the students to gain insight into themselves and their patients, and promotes a self awareness that is essential to the nurse-patient relationship and the recognition of both meaning and life pattern. In order to maximize therapeutic communication with their patients, young nurses need to learn how

to become aware of their own life patterns and the meaning that these patterns bring to their nurse-patient communication and relationship. This personal transformation may be nurtured by educators who focus on helping students become who they will be (Newman, 2007).

Health Policy

There is shift in healthcare provision that is under recognized in the United States: the increasing dependence on family and significant others of patients to assume the responsibility of caregiving as patients spend less time recovering in the hospital and more time recovering at home. There needs to be increased awareness of this issue and a mobilization of resources to support these individuals. Nursing is in a prime position to bring this issue to the forefront and affect legislative changes on the local, state, national and international levels by redefining the roles of informal caregivers and nurses.

First, nurses and nursing practice need to be sustained by adequate and appropriate organizational support and resources to be able to truly focus on their clients' needs for humanization, choice and meaning (Willis, Grace & Roy, 2008). Nurses must be allowed time to interact with their patients and the informal caregivers who will care for these patients in order to discover what is meaningful to these individuals, what their unmet needs are and what resources are necessary to support patients and caregivers through the caregiving experience.

Nursing must demonstrate through research and practice the importance of nursing involvement during the informal caregiving experience and beyond. This may be accomplished by demonstrating to the healthcare organization that the information

derived from the mutual, collaborative, ongoing relationship between the nurse and the caregiving dyad can have an effect on patient outcomes and quality of care. There needs to be focus on the allocation of resources for continued nursing involvement as caregivers and patients are discharged to home, progress through recovery and assimilate into their previous lifestyles.

There needs to be an examination of the manner in which reimbursement covers time nurses spend with patients both within and outside the institutional setting. Within the institutional setting there must be a language and a method of defining what nursing does above and beyond the prescribed interventions based within the medical model and the management of disease processes. There is a need to transform the political and economic conditions of home care to enable more equitable sharing of responsibility between family and nurses. If the focus is placed on continuation of care for both informal caregivers and recovering patients as the transition into their own environment, nurses must become politically active in regards to reimbursement for care extended outside the hospital. Nurses need to demonstrate that increased access to nursing care and presence may produce a decreased reimbursement cost over time.

Direct and indirect costs of informal caregiving, including potential health issues for informal caregivers, loss of work time, rehabilitation costs, recidivism and the resulting costs need to be addressed with reimbursement agencies. By changing the existing model of care, one that is prescriptive and primarily relegated to the hospital setting, to a model that is inclusive of understanding an individual's life patterns, nursing

will be able to create individualized interventions that may prove to be more cost effective over time.

Limitations

There were several limitations to this study. The research participants were self-selected and may have been more open to sharing their life stories and their caregiving experience than individuals who chose not to participate. All the participants expressed a desire to share their experiences in order to help other individuals who care for their spouses after coronary artery bypass surgery. The study did not capture potential issues and themes of those individuals who are already struggling with the caregiving experience and who were unwilling or unable to participate. In addition, there is a lack of ethnic and sociocultural diversity in the study and an inability to generalize the findings beyond the group studied.

Although the research design included an optional third interview, none of the participants chose to meet with the researcher. A scheduled third interview could have provided more data about how the participants' reflections affected their continued experience with caregiving.

The overall process of the research study could have been enhanced with a more seasoned researcher. Prior experience with using Newman's theory and research method could have brought forth meanings and further reflections that were not recognized by the novice researcher.

Directions for Future Research

This study produced an improved understanding of the lived experience of the spousal caregivers of coronary artery bypass surgery. There is a continued need for research that addresses the issues, concerns and meanings involved with the caregiving experience of not only the coronary artery bypass surgery caregiver population experience but of caregivers of other patient populations and health experiences.

Future studies call for more diversity within the study participants to improve understanding of the caregiving experience across different demographic variables. The influences of ethnicity, financial situation and culture on life experience and expansion of consciousness within the caregiving experience should be explored. Research involving other family caregivers could add to understanding the influence of family on the dynamics of caregiving and recovery. Based on findings from this study related to the enmeshed relationship between the spousal caregiver and the recovering spouse, it would be interesting to research the caregiving experience by interviewing and following the spousal dyad.

Intervention studies with spousal caregivers present great promise for further contributions to developing nursing knowledge and to health care delivery regarding informal caregiving. Using Newman's methodology in an intervention study could produce research that substantiates the contribution of understanding an individual's experience from the perspective of Health as Expanding Consciousness. This research may produce a new understanding in regards to the relationship between the informal caregiver and the nurse, caregiving efficacy, and caregiver burden in informal caregiving.

Intervention research should also focus on the effect of nursing interventions on recidivism rates. This would include tracking the number of repeat visits to health care providers and readmission rates and comparing these visits with a population received continued nursing involvement. There is potential for healthcare institutions to use the results of this research for the marketing of their facilities' impact on quality patient outcomes.

There is potential for instrument development regarding efficacy and development of individualized interventions. The combination of Newman's theory and Young's spectrum of human evolution holds great promise for a new understanding of how prepared an individual may be to be successful with an intervention. Furthermore, using Young's spectrum may also be a technique to measure progression through an intervention and expansion of consciousness of the individual.

This study also demonstrates the need for longitudinal research studies regarding the spousal caregiver experience. Although there is research that demonstrates the impact of this health experience on the patients, research needs to be done that focuses on the long-term effect on caregivers of these individuals. There needs to be research that focuses on the timeframe after acute recovery from surgery. This would include studies that follow spousal caregivers six months to at least one year after initiating the caregiving experience.

Potential areas of interest of research that focuses on the spousal caregiver would include the following: 1) The effects of an intervention study using Newman's methodology: How did pattern awareness and expansion of consciousness affect spousal

caregivers' future experiences as a caregiver and as an individual? Is there continued expansion of consciousness for these individual beyond of the caregiving role? 2) The effect of the caregiving experience of the dyadic relationship: How does this caregiving experience affect the dyadic relationship once the recovering spouse transitions out of the patient role? Can the spousal caregiver sustain and continue with an expansion of consciousness after the spouses' transition?

There is also great potential for research using Newman's theory and research method that focuses on the impact on nursing and the nurse-client relationship. There is an array of questions that could produce valuable information regarding nursing: How has this experience changed your relationship with your patients? How has this experience changed you as a person and as a nurse? Can you describe the difference between using the Health as Expanding Consciousness framework with your clients and not using Health as Expanding Consciousness framework? Did using the Health as Expanding Consciousness framework give you the opportunity to know your patient? Does the nurse/client relationship based within the Health as Expanding Consciousness framework provide you meaningful information that inspires potential new nursing interventions? Other research involving nursing should focus on the impact of infusing Newman's theory into the practice on nursing satisfaction, patient satisfaction, nurse retention, patient perception of quality of care.

Another area of interest is the how researchers, novice or otherwise, experience their own evolution as a human and expansion of consciousness while using Newman's methodology. The intentional presence that researchers bring to the researcher-participant

relationship when using Newman's research method has ramifications for the researcher. These may include increased awareness of self, a new understanding of the other, greater clarity to meaning and insights of study findings, and the critical importance of establishing partnerships with patients.

Finally, there is a responsibility to disseminate the knowledge generated by this research into practice. This could be accomplished by publications in peer-reviewed journals, presentations at professional conferences and with the infusion of both the research finding and the theory of Health as Expanding Consciousness into practice.

Conclusion

In conclusion, this study examined the spousal caregiving experience of recovering the CABG patient at home within the theoretical framework of Newman's Health as Expanding Consciousness. The study demonstrated the importance of understanding the uniqueness of the individual life pattern and caregiving experience. The themes that emerged from the data provided new insight into the spousal caregiver experience and the potential for expansion of consciousness. These new insights revealed important implications for nursing including further investigation into dyadic relationship disruption with caregiving, spousal caregiver uncertainty and vigilance, mutuality within the nurse-patient relationship and the impact of transformation on the perception of life left to live. The findings from this study also add to the empirical support of Health as Expanding Consciousness and demonstrate potential for the expansion of its research method.

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The Experience of the Spousal Caregiver Of the Postoperative Cardiac Surgery Patient

This is a study focused on the experiences of the individual who cares for his or her spouse after cardiac surgery.

I am looking for participants who are willing to share their caregiving experience after they return home with their spouse.

This research study aims to better understand what caregiving spouses go through and how we may better assist them in the caregiving experience.

If you are interested in participating in the study, please let the Cardiac Surgery Staff know. After your spouse's surgery, you will be contacted and receive further information regarding the study.

Thank you in advance for your consideration...

Carrie Edgerly MacLeod PhD(c), RN

Appendix B: Consent Form

Protocol Title: The Experience of the Spousal Caregiver with the Postoperative Cardiac Surgery Patient

Principal Investigator: Carrie E. MacLeod PhD (c), RN

Site Principal Investigator: Carrie E. MacLeod PhD (c), RN

Description of Subject Population: Spousal caregiver of the postoperative cardiac surgery patient

About this consent form

Please read this form carefully. It tells you important information about a research study. A member of our research team will also talk to you about taking part in this research study. People who agree to take part in research studies are called “subjects.” This term will be used throughout this consent form. If you have any questions about the research or about this form, please ask us. If you decide to take part in this research study, you must sign this form to show that you want to take part. We will give you a copy of this form to keep.

Why is this research study being done?

The purpose of the study is to learn more about a person’s experience as a caregiver. This study focuses on people who are caring for their husband or wife after open heart surgery. The results from this study will help nurses understand the issues and needs of these caregivers. This will help nurses develop interventions that will better assist these caregivers.

We are asking you to take part because your husband or wife has had cardiac surgery. About fifteen (15) people will take part in this research study. We will enroll all fifteen (15) participants at North Shore Medical Center

How long will I take part in this research study?

It will take you about one (1) month to finish the study. During this time you will be asked to meet with the researcher of the study no more than three (3) times. These meetings will be during the second, third and possibly fourth week after discharge from the hospital.

What will happen in this research study?

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- Before your husband or wife is discharged to home, you will meet with the researcher. The researcher will review the research study with you. You are free to ask any questions that you have about the study. If you agree to be part of the research study, the first meeting will be arranged for about two weeks after you are home.
- You will be asked to fill out one form. This form asks for information about your age, sex, race, education level and income and how long your husband or wife was in the hospital after surgery..
- You will be asked to keep a journal during the first two weeks at home. You may either write a daily diary or randomly write down experiences that are meaningful to you during this time.
- One week before the first scheduled interview, the researcher will call you to confirm the date and time.
- You may choose to do the interview in your home or at the hospital in the Cardiac Surgery Unit conference room. This interview will take about one hour of your time.
- The first interview will be done by the researcher. This interview will be audiotaped. You will be asked: “Could you tell me about the most meaningful people and experiences in your life and in this caregiving experience?” You may share any information that is important to you. The researcher may ask you other questions during the interview. This will help the researcher better understand your experience. You may use your journal to help you remember your experiences over the past month.
- After the interview, the researcher will listen to the tape. The researcher will write down your interview on paper. The written interview will be read many times by the researcher. This will help the researcher understand your experience. Your written interview will be given a number. From that point on, only that number will be used during the study. The researcher will not use your name or any information that may identify you.
- One week after the first interview, the researcher will meet with you either in your home or at the hospital in the Cardiac Surgery Unit conference room to review your interview. This meeting will give you a chance to read your interview. You will be given the time to add, delete or change any information. The researcher will talk with you about what she found to be meaningful in your interview. You will be given the

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time to discuss these findings with the researcher. This meeting will take about one hour of your time.

- A third meeting can be arranged if you would like to meet again. This will give you time to talk about any changes that you made to your interview during the second meeting. It will also give you the time to talk about any further information that you feel is important. If you choose not to meet for a third time, then a telephone interview will take place within one week of the second interview.
- If you are unable to meet with the researcher at the arranged times, then the meetings will be rescheduled for a better time. This will be done over the telephone or by mail.
- The researcher will then add your interview with the other participants' interviews. All of the interviews will be read many times by the researcher. This will help the researcher identify experiences that were present for all the participants. This information will help the research better understand the caregiving experience.

What are the risks and possible discomforts from being in this research study?

Sharing some of your feelings during the interview may make you feel uncomfortable. Licensed counselors are available if you need to speak with someone. You may ask for this referral at any time during the research study. If you choose to speak with someone, it will not affect your spouse's care or your relationship with the Cardiac Surgery team.

What are the possible benefits from being in this research study?

The results from this study will help nurses understand the issues and needs of these caregivers. This will help nurses develop interventions that will better assist these caregivers.

The results of this research study will be used to plan further research.

Can I still get medical care within Partners if I don't take part in this research study, or if I stop taking part?

Yes. Your decision won't change the medical care you get within Partners now or in the future. There will be no penalty, and you won't lose any benefits you receive now or have a right to receive.

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Taking part in this research study is up to you. You can decide not to take part. If you decide to take part now, you can change your mind and drop out later. We will tell you if we learn new information that could make you change your mind about taking part in this research study.

If you take part in this research study, and want to drop out, you should tell us.

It is possible that we will have to ask you to drop out before you finish the study. If this happens, we will tell you why. We will also help arrange other care for you, if needed.

Will I be paid to take part in this research study?

You will receive a \$25.00 gift certificate to a local restaurant. This is to thank you for being part of the study.

What will I have to pay for if I take part in this research study?

There will be no cost to you for taking part in the study.

What happens if I am injured as a result of taking part in this research study?

Since this is an information gathering research study, the risk of injury is extremely unlikely. However should any injury occur, we will offer you the care needed to treat any injury that directly results from taking part in this research study. We reserve the right to bill your insurance company or other third parties, if appropriate, for the care you get for the injury. We will try to have these costs paid for, but you may be responsible for some of them.

Giving you care does not mean that Partners hospitals or researchers are at fault, or that there was any wrongdoing. There are no plans for Partners to pay you or give you other compensation for the injury. However, you are not giving up any of your legal rights by signing this form.

If you think you have been injured or have experienced a medical problem as a result of taking part in this research study, tell the person in charge of this study as soon as possible. The researcher's name and phone number are listed in the next section of this consent form.

If I have questions or concerns about this research study, who can I call?

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You can call the researcher with your questions or concerns. Our telephone numbers are listed below. Ask questions as often as you want.

Carrie E. MacLeod is the person in charge of this research study.
508-451-0213.
Monday through Friday from 7 AM to 7 PM.

If you have questions about the scheduling of appointments or study visits:
Carrie E. MacLeod
508-451-0213
Monday through Friday, 7 AM to 7 PM.

If you want to speak with someone **not** directly involved in this research study, please contact Charles A. Bockoff, MD., Chairman, North Shore Medical Center Institutional Review Board
at 781-477-3678.

You can talk to them about:

- Your rights as a research subject
- Your concerns about the research
- A complaint about the research

Also, if you feel pressured to take part in this research study, or to continue with it, they want to know and can help.

If I take part in this research study, how will you protect my privacy?

Federal law requires Partners (Partners HealthCare System and its hospitals, health care providers and researchers) to protect the privacy of health information that identifies you. This information is called Protected Health Information. In the rest of this section, we refer to this simply as “health information.”

If you decide to take part in this research study, your health information may be used within Partners and may be shared with others outside of Partners, as explained below.

We have marked with a ☒ how we plan to use and share your health information. If a box is not checked ☐, it means that type of use or sharing is not planned for in this research study.

We will also give you the **Partners Notice for Use and Sharing of Protected Health Information**. The Notice gives more details about how we use and share your health information.

▪ **Health Information About You That Might be Used or Shared During This Research**

- ☐ Information from your hospital or office health records within Partners or elsewhere, that may be reasonably related to the conduct and oversight of the research study. If health information is needed from your doctors or hospitals outside Partners, you will be asked to give permission for these records to be sent to researchers within Partners.
- ☐ New health information from tests, procedures, visits, interviews, or forms filled out as part of this research study

▪ **Why Health Information About You Might be Used or Shared with Others**

The reasons we might use or share your health information are:

- To do the research described above
- To make sure we do the research according to certain standards - standards set by ethics and law, and by quality groups
- For public health and safety - for example, if we learn new health information that could mean harm to you or others, we may need to report this to a public health or a public safety authority
- For treatment, payment, or health care operations

▪ **People and Groups That May Use or Share Your Health Information**

1. People or groups within Partners

- ☒ Researchers and the staff involved in this research study
- ☒ The Partners review board that oversees the research
- ☒ Staff within Partners who need the information to do their jobs (such as billing, or for overseeing quality of care or research)

2. People or groups outside Partners

- ☒ People or groups that we hire to do certain work for us, such as data storage companies, our insurers, or our lawyers
- ☒ Federal and state agencies (such as the U.S. Department of Health and Human Services, the Food and Drug Administration, the National Institutes of Health, and/or the Office for Human Research Protections) and other U.S. or foreign government bodies, if required by law or involved in overseeing the research

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- ☒ Organizations that make sure hospital standards are met
- ☐ The sponsor(s) of the research study, and people or groups it hires to help perform this research study
- ☐ Other researchers and medical centers that are part of this research study
- ☐ A group that oversees the data (study information) and safety of this research study
- ☐ Other:

Some people or groups who get your health information might not have to follow the same privacy rules that we follow. We share your health information only when we must, and we ask anyone who receives it from us to protect your privacy. However, once your information is shared outside Partners, we cannot promise that it will remain private.

▪ Time Period During Which Your Health Information Might be Used or Shared With Others

- Because research is an ongoing process, we cannot give you an exact date when we will either destroy or stop using or sharing your health information.

▪ Your Privacy Rights

- You have the right **not** to sign this form permitting us to use and share your health information for research. If you don't sign this form, you can't take part in this research study. This is because we need to use the health information of everyone who takes part in this research study.
- You have the right to withdraw your permission for us to use or share your health information for this research study. If you want to withdraw your permission, you must notify the person in charge of this research study in writing.

If you withdraw your permission, we will not be able to take back information that has already been used or shared with others. This includes information used or shared to carry out the research study or to be sure the research is safe and of high quality.

If you withdraw your permission, you cannot continue to take part in this research study.

- You have the right to see and get a copy of your health information that is used or shared for treatment or for payment. To ask for this information, please contact the person in charge of this research study.

▪ **If Research Results Are Published or Used to Teach Others**

The results of this research study may be published in a medical book or journal, or used to teach others. However, your name or other identifying information **will not** be used for these purposes without your specific permission.

Consent to take part in this research study, and authorization to use or share your health information for research

Statement of Subject or Person Giving Consent

- I have read this consent form.
- This research study has been explained to me, including risks and possible benefits (if any), other options for treatments or procedures, and other important things about the study.
- I have had the opportunity to ask questions.

If you understand the information we have given you, and would like to take part in this research study, and also agree to allow your health information to be used and shared as described above, then please sign below:

Signature of Subject:

Subject

Date/Time

OR

If you understand the information we have given you, and would like to give your permission for the person you are authorized to represent to take part in this research study, and also agree to allow his/her health information to be used and shared as described above, then please sign below:

Signature of Parent(s)/Guardian or Authorized Representative:

Parent(s)/Guardian of Minor

Date/Time

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OR

Court-appointed Guardian or Health Care Proxy

Date/Time

OR

Family Member/Next-of-Kin

Date/Time

Relationship to Subject:_____

Signature of a Witness (when required by the PHRC or by the Sponsor):

Witness (when required)

Date/Time

Statement of Study Doctor or Person Obtaining Consent

- I have explained the research to the study subject, and
- I have answered all questions about this research study to the best of my ability.

Study Doctor or Person Obtaining Consent

Date/Time

In certain situations, the Partners Human Research Committee (PHRC) will require that a subject advocate also be involved in the consent process. The subject advocate is a person who looks out for the interests of the study subject. This person is not directly involved in carrying out the research. By signing below, the subject advocate represents

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(or “says”) that the subject has given meaningful consent to take part in the research study.

Statement of Subject Advocate Witnessing the Consent Process

- I represent that the subject, parent(s), or legally authorized individual signing above has given meaningful consent.

Subject Advocate
(if required by the PHRC or sponsor for this study)

Date/Time

Consent Form Version Date: 1/07/08

Demographic Information

Age

Less than 50 years of age

50-60 years old

60-70 years old

70-80 years old

80-90 years old

Greater than 90 years old

Gender

Male

Female

Years Married

Ethnicity

Anglo-American

African-American

Asian

Hispanic

Other

Education

Less than high school

High school graduate

Partial College

College graduate

Post-graduate degree

Socioeconomic Status

< \$20,000/year

\$41-60,000/year

\$61-80,000/year

\$81-100,000/year

>\$100,000/year

Length of Postoperative Hospital Stay

Table 1: *Review of Caregiver Burden Scales*

Scale Name	Items/Format	Comments
The Burden Interview (Zarit, 1983)	Self administered survey. 22 items; 5 point Likert scale, responses range from not at all to extremely	Questions focus on caregiver's health, psychological well being, finances, social life and relationship between caregiver and partner. The total score ranges from 0 to 88. A high score correlates with higher level of burden.
Cost of Care Index (Kosberg et al, 1986)	Self-administered survey 20 items; 4 point Likert scale. Responses range from Strongly Agree to Strongly Disagree	Subscales <ul style="list-style-type: none"> • Subjective-value • Objective- personal/social; physical/emotional; health; provocateur; economic All items summed for total score. Each domain may have separate summed score. High scores identifies high risk caregivers of sick or elderly persons and can be worded pre-caregiving and during caregiving.
Caregiver Burden Measures (Siegel et al, 1991)	Each domain has a specific focus and is considered a single item. Scores in each domain are recorded to range from 0 (no burden) to 3 (high burden).	5-domains: Employment, Financial, Physical, Social, Time. Global Burden is the sum of each of the five domain values. Scores in each domain are recorded to range from 0 (no burden) to 3 (high burden). Time burden is coded using several items and then calculating a single code of average number of help per week is provided.
Caregiver Strain Index (Robinson, 1983)	Self administered survey. 13 items, dichotomous response (yes/no). . Positive responses to seven or more items on the index indicate a greater level of strain.	Measures objective strain and does not include subjective measures. This instrument can be used to assess individuals of any age who have assumed the role of caregiver for an older adult. Scores can range from 0 to 13; a higher CSI score indicates a greater burden of caregiving.
Caregiver Burden (Stull, 1994)	Structured, telephone interview. Items are scored on 5-point scales, response range from "never" to "all of the time".	Measures care receiver need, caregiver well-being, caregiver burden, and outcomes of caregiving for elderly people living in the community. The domains for burden (physical strain, social constraints, financial strain) are parallel to those for generic well-being (physical health, social activities, income).
Caregiver Burden Inventory (Novak, 1989)	24- item scale. Items are scored on a 4-point scale, responses range from "not at all descriptive" to "very descriptive".	Multi-dimensional scale with both subjective and objective measures. Designed to assess the experience of caregivers of cognitively impaired older people. 5 factors: Time Dependence, Developmental Behavior, Physical Burden, Social Burden, Emotional Burden. Quantifies the global burden according to a total score (higher score = higher burden) and evaluates and quantifies different aspects of burden through its subgroups and respective scores.

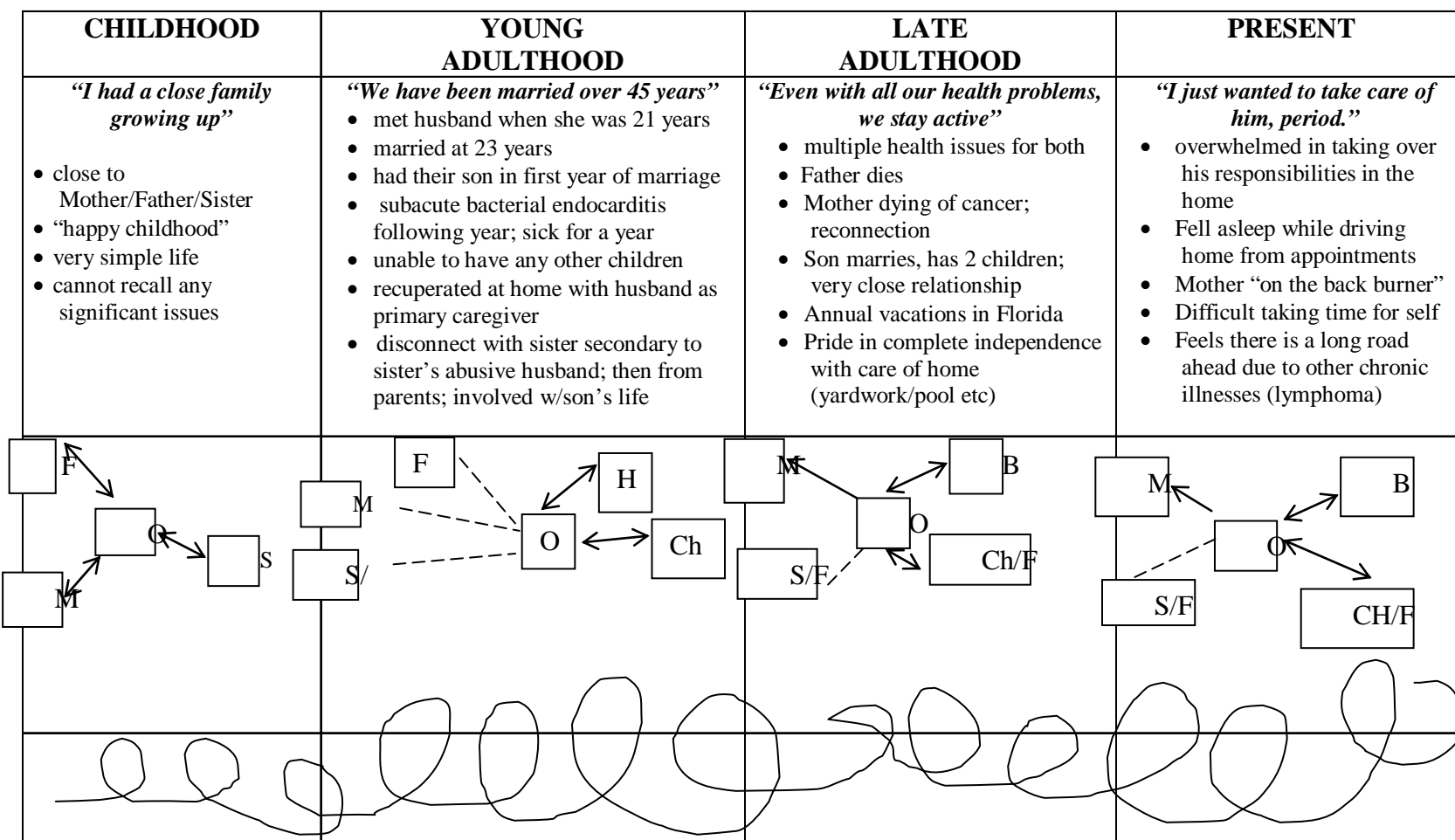


Figure 4. Participant #1 Olga (O): H: husband; F: father; M: mother; S: sister; S/F: sister and family; Ch: son; Ch/F: son and his family

CHILDHOOD	YOUNG ADULthood	LATE ADULthOOD	PRESENT
<p><i>“Typical sort of childhood”</i></p> <ul style="list-style-type: none"> • Close to parents, 2 brothers and 1 sister • lot of good clean fun with friends. • Never really like school 	<p><i>“She waited for me until I got out of the military.”</i></p> <ul style="list-style-type: none"> • Left high school senior year and joined the Army • Never dated anyone else • Married after military training (two years) • Two children: daughter/son • Worked two jobs to “make ends meet • Remains close to sister/family. Brothers moved away 	<p><i>“We have always worked hard, me at work and her at home.”</i></p> <ul style="list-style-type: none"> • J works 2 jobs; W works part time • Both children graduate from high school • Daughter marries; one child who is born with neurological disorder • Parents pass away • Very close with daughter and her family; “soft spot” for his grand-daughter • Doesn’t reflect on relationship with his son • Wife “rules the roost” 	<p><i>“I just do what she wants me to”</i></p> <ul style="list-style-type: none"> • J uses computer to educate himself and his wife • Son trying to help with W’s recovery • Co-existing issues with grand-daughter’s health • Went back to work one week after W return to home • J doesn’t like to “ruffle” wife’s feathers

Figure 5. Participant #2 Jim (J): W: wife/care recipient; F: father; M: mother; B1: brother 1; B2: brother 2; S: sister; S/F: sister and her family; Fr: friends; Ch1: daughter; Ch1/F: daughter and her family; Ch2: son

CHILDHOOD	EARLY ADULthood	ADULthOOD	LATE ADULthOOD	PRESENT
<p><i>“I never had to put up with, well not put up with, any bad sort of stuff”</i></p> <ul style="list-style-type: none"> • youngest; 2 brothers and 2 sisters; close to oldest sister • Mother more present than father • Youngest brother ill • close friends • felt bit spoiled as the youngest 	<p><i>“So I met my husband when I was young, 18 and we got married and I moved up North.”</i></p> <ul style="list-style-type: none"> • Married young • Husband older, in military; met at dance • no desire to go to college • felt secure; some financial issues • brother dies • increasing distance from family 	<p><i>“You just had to accept it and stop worrying about it.”</i></p> <ul style="list-style-type: none"> • Reliance and social closeness with each other • Unable to have children; • Worked PT • Very active physically • both parents die • Other brother dies 	<p><i>“As a wife, I usually do get things for him. I guess I baby him.”</i></p> <ul style="list-style-type: none"> • Feels fortunate that she and husband were older before health issues ensued • Husband diagnosed with renal cell cancer; has nephrectomy • reliance on each other • appreciates life more than husband • Close to godson 	<p><i>“You accept these things more when you older than when you are younger. I have accepted a lot and he is going to need to accept a lot more too.”</i></p> <ul style="list-style-type: none"> • tends to over do. • Not ready to bring him home • stressed/depressed • No external support • need to address her own health • schedules disrupted

Figure 6. Participant #3 Katherine (K), M: mother, F: Father, S1:oldest sister, S2: sister, B1: older brother, B2: younger brother, Fr: friends, G: Godson

CHILDHOOD	EARLY ADULthood	ADULthOOD	LATE ADULthOOD	PRESENT
<p><i>“My older brother was like a father to me.”</i></p> <ul style="list-style-type: none"> Father died of a heart attack when Bill was 5 Close to his 2 brothers/1 sister. Bill #3 of 4. Mother remarried. Stepfather “he was trash”. Stepfather left brothers were born Portrays mother as “hardworker” Older brother= father figure 	<p><i>“She came into the store I worked at.”</i></p> <ul style="list-style-type: none"> military directly after high school Hurt back in military; early discharge Met wife He was 23, she 18. He worked in local store. 	<p><i>“Am I going to make it past what my father did?”</i></p> <ul style="list-style-type: none"> Lost job and pension; took a job as a truck driver. Worried he would not live as long as his father Bill’s mother dies Has 2 sons 	<p><i>“I don’t expect my other son to be here.”</i></p> <ul style="list-style-type: none"> not watching his own health closely Knee surgery, HTN, gout Close relationship with one son; Other son is “too busy” Enjoys golf/yardwork Sister dies of heart attack. Wife with anginal symptoms 	<p><i>“She knows what she wants all the time...“I just did what they told me to do.”</i></p> <ul style="list-style-type: none"> Wife kept him calm by telling him what to do Son lives with them; very helpful Disbelief at how well wife has done Acknowledges he wouldn’t be doing as well without help from son

Figure 7. Participant #4 Bill (B) M: Mother, F: Father, SF: Stepfather, S: sister, HB: half brothers, B1: older brother, B2: younger brother, W: wife, S1: older son, S2: younger son

CHILDHOOD	EARLY ADULthood	ADULthOOD	LATE ADULthOOD	PRESENT
<p><i>“I loved her but it was hard.”</i></p> <ul style="list-style-type: none"> Mother had depressive episodes; not close. Knew husband growing up Father “hurt” by mother’s illness 	<p><i>“I never took total care of her.”</i></p> <ul style="list-style-type: none"> Met H at church; M 10 y younger Married at 17 years mother was glad she got married and left the house Finished high school Parents lived down the street Mother institutionalized for depression Father died of lung cancer Has two children: boy and girl 	<p><i>“Sometimes you have to put your own family first”</i></p> <ul style="list-style-type: none"> Mother readmitted. M not involved b/c of caring for her own children Husband with steady work. M gave piano lessons from her home Mother begins to want to spend more time with M 	<p><i>“I feel like I have to be in shape to take care of him</i></p> <ul style="list-style-type: none"> Married 49 years; lived in same home since marriage 2 grandsons Has a bad back; uses acupuncture Sister died lung cancer Mother died 	<p><i>“I feel like I have to think for the two of us and I tell you, that is hard work.”</i></p> <ul style="list-style-type: none"> 1st week “horrible” Difficulty/ dietary changes Teaches piano and plays at church Vigilance: husband does not always remember CABG Difficult to find help so she can do errands/work

Figure 8. Participant# 5 Madeleine (M). H: husband, Mo: mother, F: father, S1: sister, S2: sister, Fr: friends, S: son, D: daughter,

CHILDHOOD	EARLY ADULthood	ADULthOOD	LATE ADULthOOD	PRESENT
<p>“I was the youngest and everyone took care of me.”</p> <ul style="list-style-type: none"> • Youngest of 6 children; Very close • Didn’t have \$\$ but had “a lot of fun” • Affectionate, loving parents • Large circle of friends between her own and siblings • Viewed family as well respected and good people 	<p>“...my father said G was a good man and that meant the world to me.”</p> <ul style="list-style-type: none"> • Married • J just finished college; did not go to work • “fit right into the family” • Moved to G’s home state • Brother 1 killed in Korean War; J pregnant with 1st child. G very supportive • Had 2 more children (girl/boy) 	<p>“I wanted my children to have the same kind of childhood that I did.”</p> <ul style="list-style-type: none"> • Mother and Father die • All children healthy & happy • Loved being stay at home mother • Active social life 	<p>“G likes to be in control and that has always been okay for us.”</p> <ul style="list-style-type: none"> • Brother 2 dies • Sister 1 dies breast cancer • Active social life • close to surviving siblings • Feeling “creaky” but healthy • Surprised she is as old as she is; feels like in 50’s. 	<p>“I usually go along with what everyone else wants to do so it was a new experience for me.”</p> <ul style="list-style-type: none"> • doesn’t think G understands; very difficult • Vigilant • Seems like mothering • No time for self; has lost weight, very tired

Figure 9. Participant #6 Jennifer (J): Jennifer F: Father M: Mother, B: Brothers 1,2,3; S: Sister 1,2,3; Fr: friends; G: husband; Jo: son #1, E: daughter, W: son #2

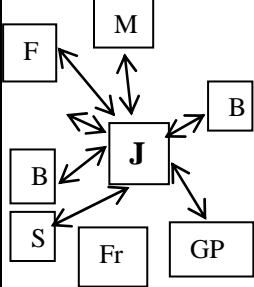
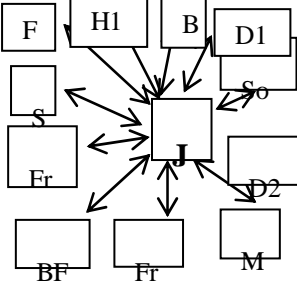
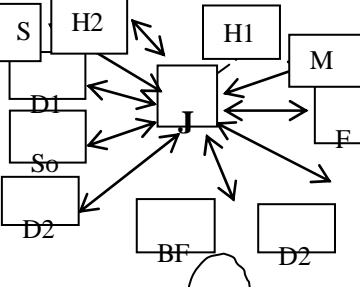
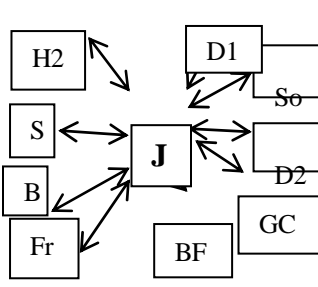
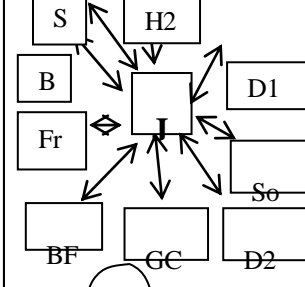
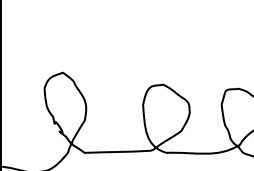
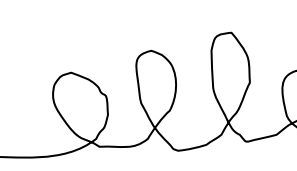

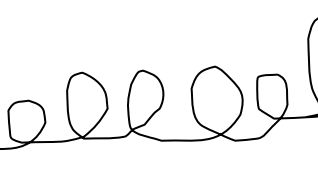
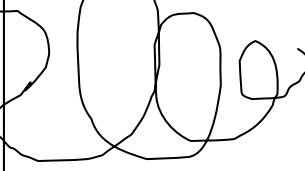
CHILDHOOD	EARLY ADULthood	ADULthOOD	LATE ADULthOOD	PRESENT
<p><i>“A wonderful time in my life...”</i></p> <ul style="list-style-type: none"> • Great childhood • Eldest of 3; 1 brother, 1 sister • Close relationship w/extended family • Loved school, always wanted to be a nurse • Close to her school friends, siblings, cousins 	<p><i>“So very busy, growing up and having my kids!”</i></p> <ul style="list-style-type: none"> • Loved school • Close to one cousin “best friend”. • Met her first husband • Married immediately graduation • financial struggle but had a good relationship w/husband • Grandparents die • Started her family: 3 children (girl/boy/girl) 	<p><i>“So much happening, both good and bad.”</i></p> <ul style="list-style-type: none"> • “typical suburban life” • Stayed at home • First husband • Great support from friends, extended family. Focuses on her children • Both her parents die • Children go to college. Meets Second Husband 	<p><i>“A wonderful start to the rest of my life.”</i></p> <ul style="list-style-type: none"> • Strong, mutual relationship w/husband #2. • very social • Close to siblings • Physically active • “very happy time” • H#2 retires 	<p><i>“Thank God we are going to be all right.”</i></p> <ul style="list-style-type: none"> • Shocked heart diagnosis • Grateful he is alive • Trying not to “hover” • Eager to resume prior lifestyle • Educating on dietary/lifestyle changes • Overwhelmed by what she didn’t know • Fears being alone
				
				

Figure 10. Participant #7 Joan (J): Mother (M), Father (F); Brother (B), Sister (S); Grandparents (GP); Friends (Fr); First husband (H1), Second husband (H2), Daughter #1 (D1), Son (So), Daughter #2 (D2), Grandchildren (GC); Best friend (BF)

CHILDHOOD	EARLY ADULTHOOD	ADULTHOOD	PRESENT
<p><i>“I have nothing but wonderful memories as a child.”</i></p> <ul style="list-style-type: none"> • childhood as happy • 2nd of 3 children; older sister, younger brother • Enjoyed school & school play; close friends and cousins 	<p><i>“I knew my husband was the one after our first date.”</i></p> <ul style="list-style-type: none"> • Met husband Jr. year @ college • married @ 26 yo • Worked as elementary school teacher • Had children early 30’s: 3 children (2 boys/1 girl) • “middle class” 	<p><i>“We were living the ‘all American dream’.”</i></p> <ul style="list-style-type: none"> • marriage strong and solid • Proud of children • nervous i.e. husband’s health (diabetic, smoker, high cholesterol) • Trying to make changes in diet, exercise for whole family 	<p><i>“This is going to change the rest of our lives.”</i></p> <ul style="list-style-type: none"> • “blown away” by need for heart surgery • Happy that husband is having OR now before he damages his heart • Overwhelmed blending work/care of husband/kids • Questions impact on children’s • fatigue, worry and can’t use usual coping; afraid to leave husband alone. • Feels connected and protective of husband

Figure 11. Participant # 8 Susan(S): Husband (H); Mother (M), Father (F); Sister (Si) Brother (B) Grandparents (GP), Friends (Fr); Cousins (Cs); Son 1 (S1), Son 2 (S2), Daughter (D), (W)Work Life

CHILDHOOD	EARLY ADULthood	ADULthOOD	LATE ADULthOOD	PRESENT
<p><i>“My mother was my girlfriend.”</i></p> <ul style="list-style-type: none"> • Close to father and brothers • Extremely close to mother and 3 aunts 	<p><i>“He is a really good husband; I really lucked out.”</i></p> <ul style="list-style-type: none"> • Met husband at 18 yo; married at 20 yo. • Lived at home w/parents; very close to mother • Moved home after married while husband in service • Had son @ 21y, daughter @ 24y • Stayed at home with children 	<p><i>“For that we did a good job, didn’t we?”</i></p> <ul style="list-style-type: none"> • Built a new home • Remained extremely close to parents • Father dies (? Cancer) • Took care of brother 1 who dies of lung cancer • Brother 2 dies • Son and daughter start own families • Cared for maternal aunt (Alzheimer’s) • 2 aunts die 	<p><i>“Well, we thought that we had been doing everything right.”</i></p> <ul style="list-style-type: none"> • Mother passes away @ 94; lived with R& J • Very close to son, daughter and their families • Husband is religious but R is not • Watches 5 grandchildren every weekend. • active social life • R & J do everything together 	<p><i>“I know I can be bossy...I do know what I am talking about and I know how to help people get better and he is.”</i></p> <ul style="list-style-type: none"> • didn’t believe J was sick. Feels terrible about this • distrust in physicians • Supportive friends; limits visitors • pushes husband to look forward • unevenness of recovery

Figure 12. Participant #10 Ruth (R): Ruth; J: husband; F: father; M: mother; B1 & B2: brothers; A 1-3: aunts; Fr: friends; S: Son; D: Daughter

Childhood	Early Adulthood	Adulthood	Late Adulthood	Present
<p><i>“I had a lovely childhood.”</i></p> <ul style="list-style-type: none"> • childhood simple, fun • One older brother; very close • very scared about Pearl Harbor • Loved school • Parents loving and supportive 	<p><i>“I knew he was the one for me.”</i></p> <ul style="list-style-type: none"> • Completed high school • Worked as secretary; Met H • Close w/ “local friends” • Stressful while H in law school • Married • Remained in town she grew up in • Waited to have children for 5 yrs • “Careful finances” 	<p><i>“The years just flew by...busy and happy.”</i></p> <ul style="list-style-type: none"> • Children: 2 girls, 1 boy. • “traditional roles” • Husband worked long hours • No health issues • Busy social • close relationship with her parents/sibling and his family 	<p><i>“It is hard when you know you are getting older.”</i></p> <ul style="list-style-type: none"> • M and F die • Very close w/children • “slowing down” physically but not mentally • H health issues: CAD, DM • J “cancer scare” but no cancer • she and H are “getting on” 	<p><i>“I feel older now than I ever have.”</i></p> <ul style="list-style-type: none"> • shocked she was so surprised about CAD diagnosis • children “surrounded me • waiting for “other shoe to drop” • Feels like “a mother again” • Doesn’t want to leave him alone • fatigue, nervous energy • prefers to keep the “house quiet

Figure 13. Participant #12 Judy (J): H: husband; F: father; M: mother; B: brother; B/f: brother and his family; Fr: friends; D1: first daughter; D2: second daughter; S: son. GC: grandchildren; PG: professional social group